

# BCSALUT 2017

II Jornades de Biblioteques i Salut de Catalunya  
Barcelona, 8 i 9 de juny

Una aproximació a la ciència oberta des de l'àmbit de la salut

Remedios Melero (IATA –CSIC)

Membre del grup [Acceso Abierto a la Ciencia](#) i [Maredata](#)

Partner del projecte [FOSTER plus](#)

[rmelero@iata.csic.es](mailto:rmelero@iata.csic.es)



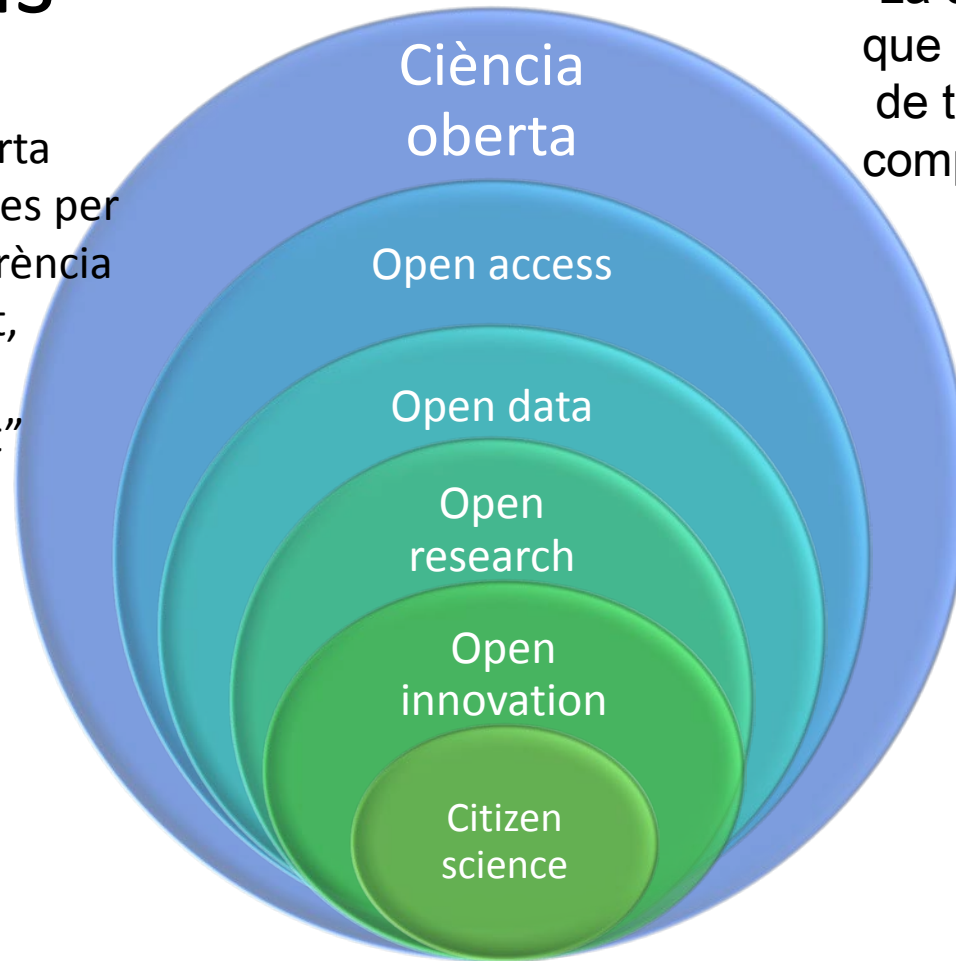


*“La  
informació  
em  
persegueix”*



# Ciència oberta un envoltant de “opens”

“La ciència oberta proporciona eines per facilitar transparència, reproductibilitat, disseminació de coneixement”



“La ciència oberta és la idea que el coneixement científic de tot tipus ha de ser compartit obertament”

“Col.laboració, reutilització, lliure distribució i la reproducció de la investigació”

## Open Science: One Term, Five Schools of Thought. Benedikt Fecher & Sascha Friesike

[http://book.openingscience.org/basics\\_background/open\\_science\\_one\\_term\\_five\\_schools\\_of\\_thought.html](http://book.openingscience.org/basics_background/open_science_one_term_five_schools_of_thought.html)

Tecnologia

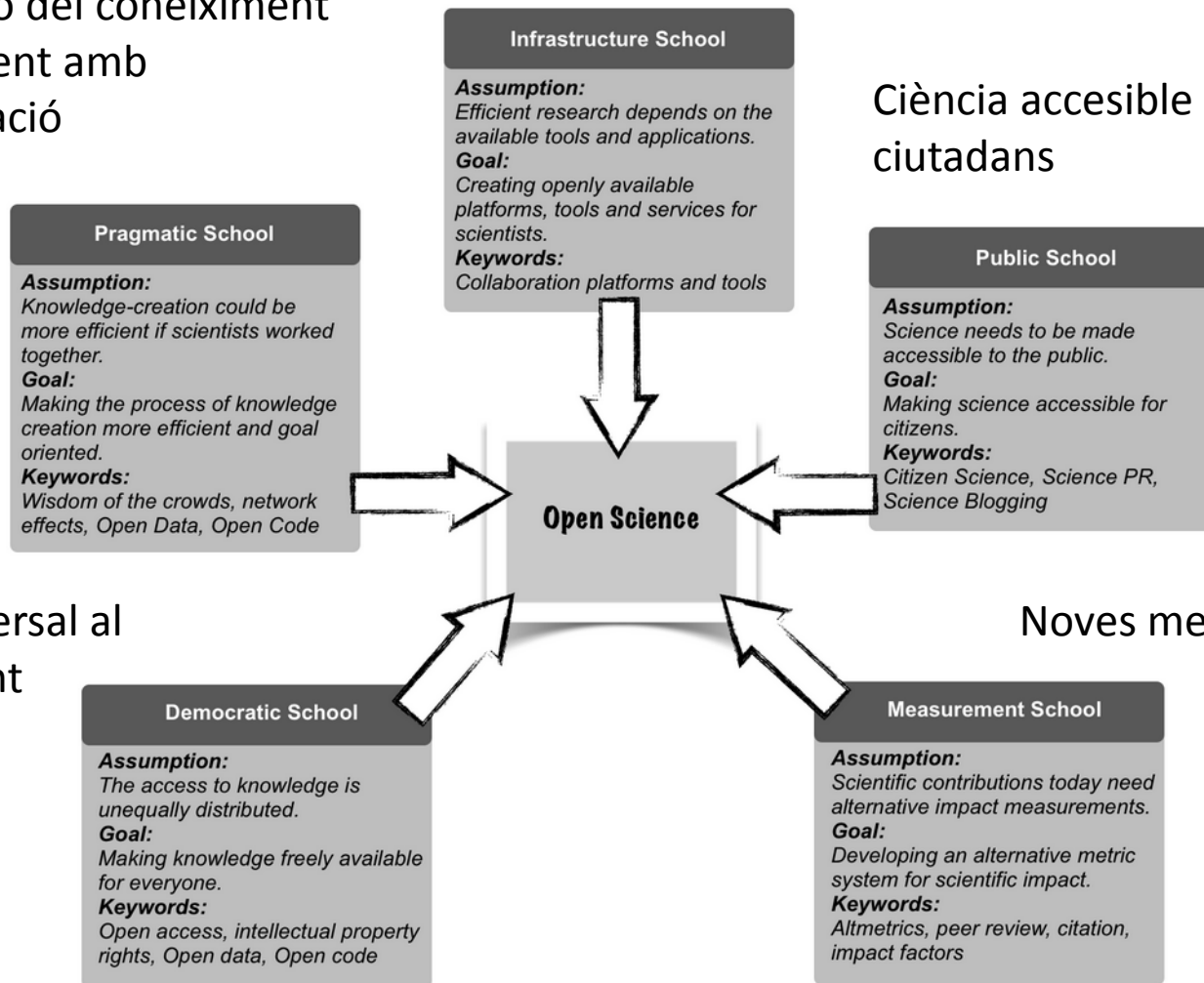
“Digestió d’altres fonts”

Generació del coneixement  
mes eficient amb  
col.laboració

Ciència accessible als  
ciutadans

Acces universal al  
coneixement

Noves me triques

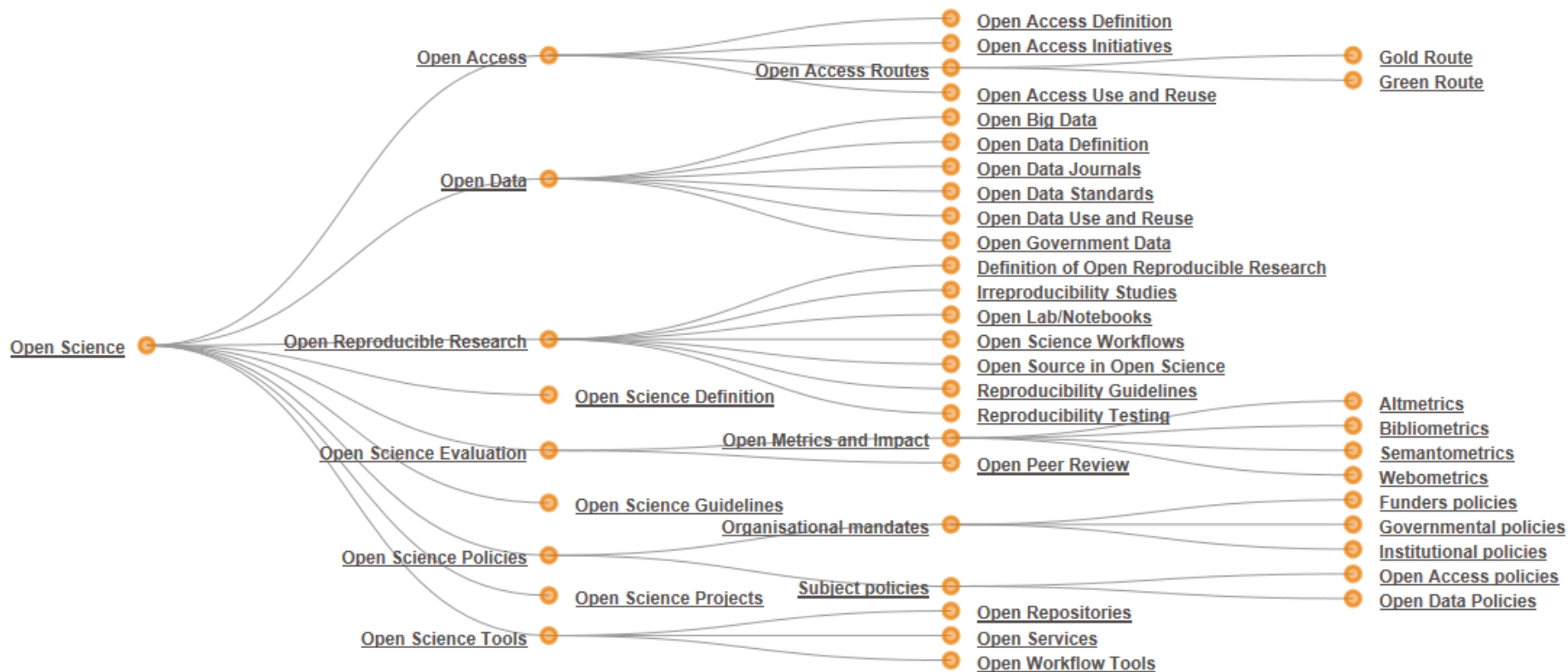


Open Science

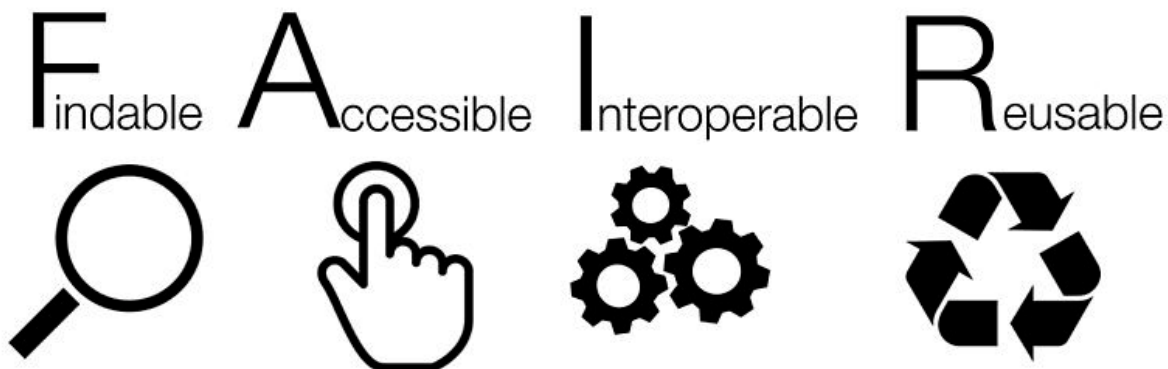
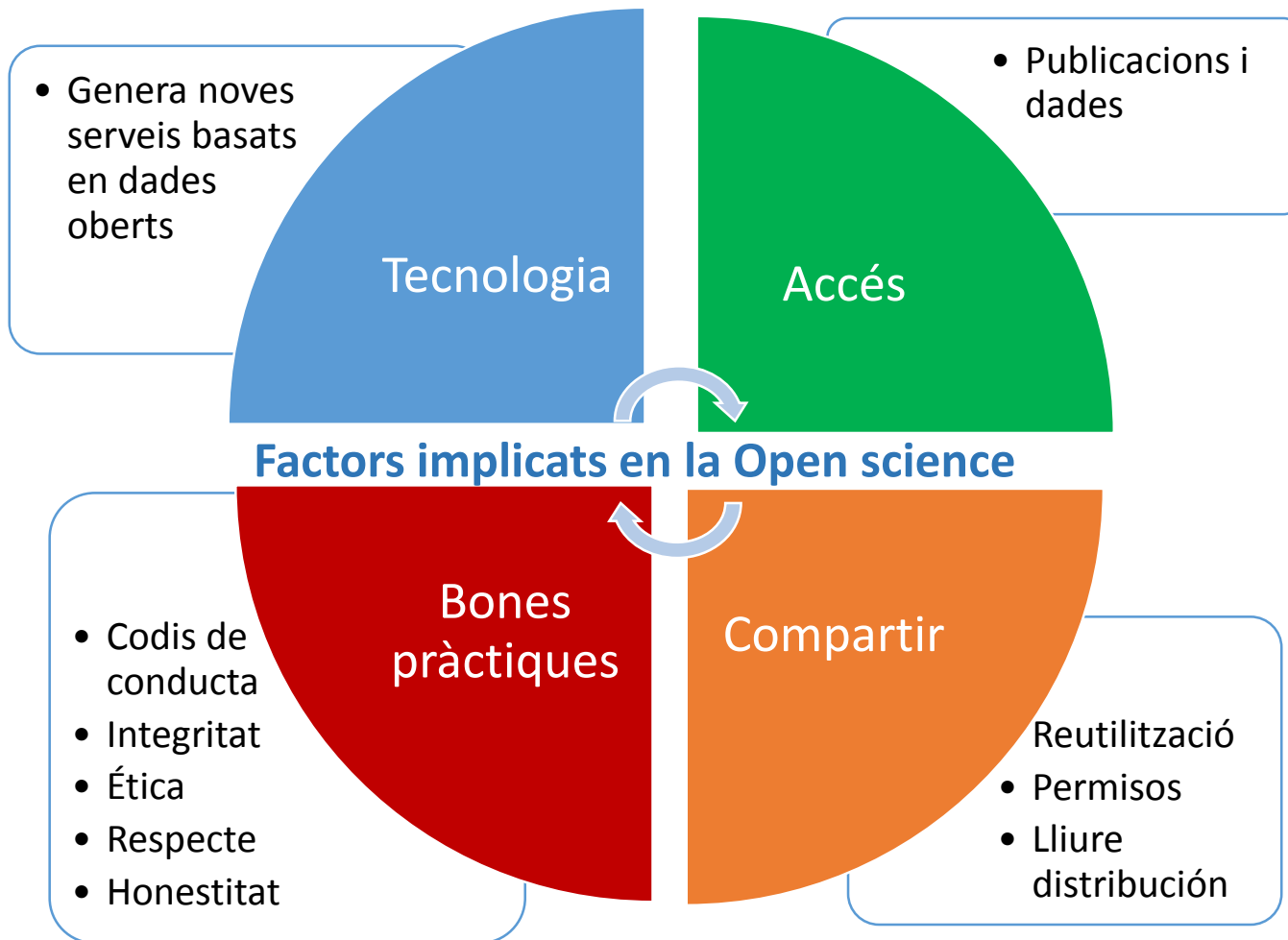
Research Data Management

Ethics

Legal Issues



<https://www.fosteropenscience.eu/>



Principis FAIR

<https://www.force11.org/group/fairgroup/fairprinciples>

McKiernan, E. C., Bourne, P. E., Brown, C. T., Buck, S., Kenall, A., Lin, J., ... Yarkoni, T. (2016). How open science helps researchers succeed. *eLife*, 5, e16800. <http://doi.org/10.7554/eLife.16800>

## Per a qué, per qué?

### **Publishing**

- Open publications get more citations
- Open publications get more media coverage
- Prestige and journal impact factor
- Rigorous and transparent peer review
- Publish where you want and archive openly
- Retain author rights and control reuse with open licenses
- Publish for low-cost or no-cost

### **Funding**

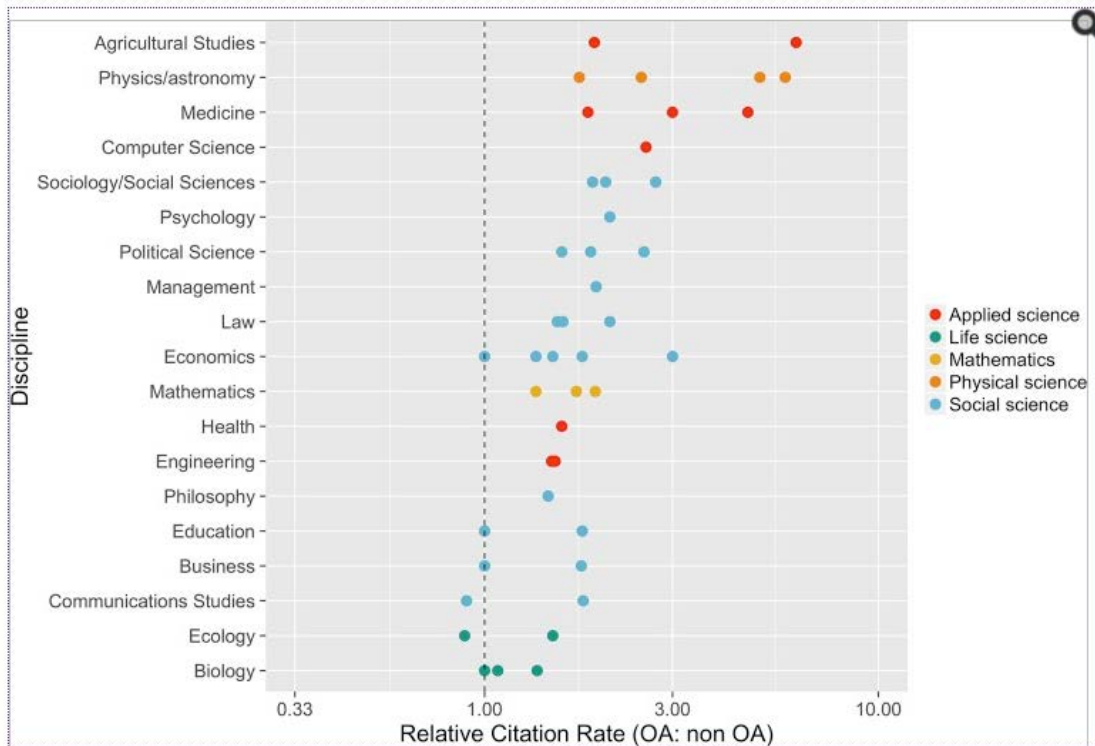
- Awards and special funding
- Funder mandates on article and data sharing
- Resource management and sharing
- Awards and special funding
- Funder mandates on article and data sharing

### **Resource management and sharing**

- Documentation and reproducibility benefits
- Gain more citations and visibility by sharing data

### **Career advancement**

- Find new projects and collaborators
- Institutional support of open research practices



Open access articles get more citations.

OpenDOAR

DOAJ  
DIRECTORY OF  
OPEN ACCESS  
JOURNALS

6  
odoi

DataCite

Acceso Abierto

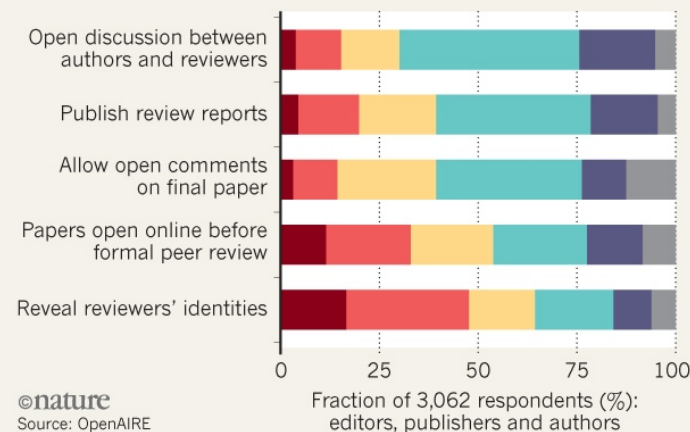
SHERPA/R•MEO

## OPENING UP PEER REVIEW

A poll finds support for making peer-review reports public, but less enthusiasm for revealing reviewers' identities.

*“Will ‘X’ make peer review better, worse, or have no effect?”*

■ Much worse ■ Worse ■ Neither better nor worse  
■ Better ■ Much better ■ Don't know

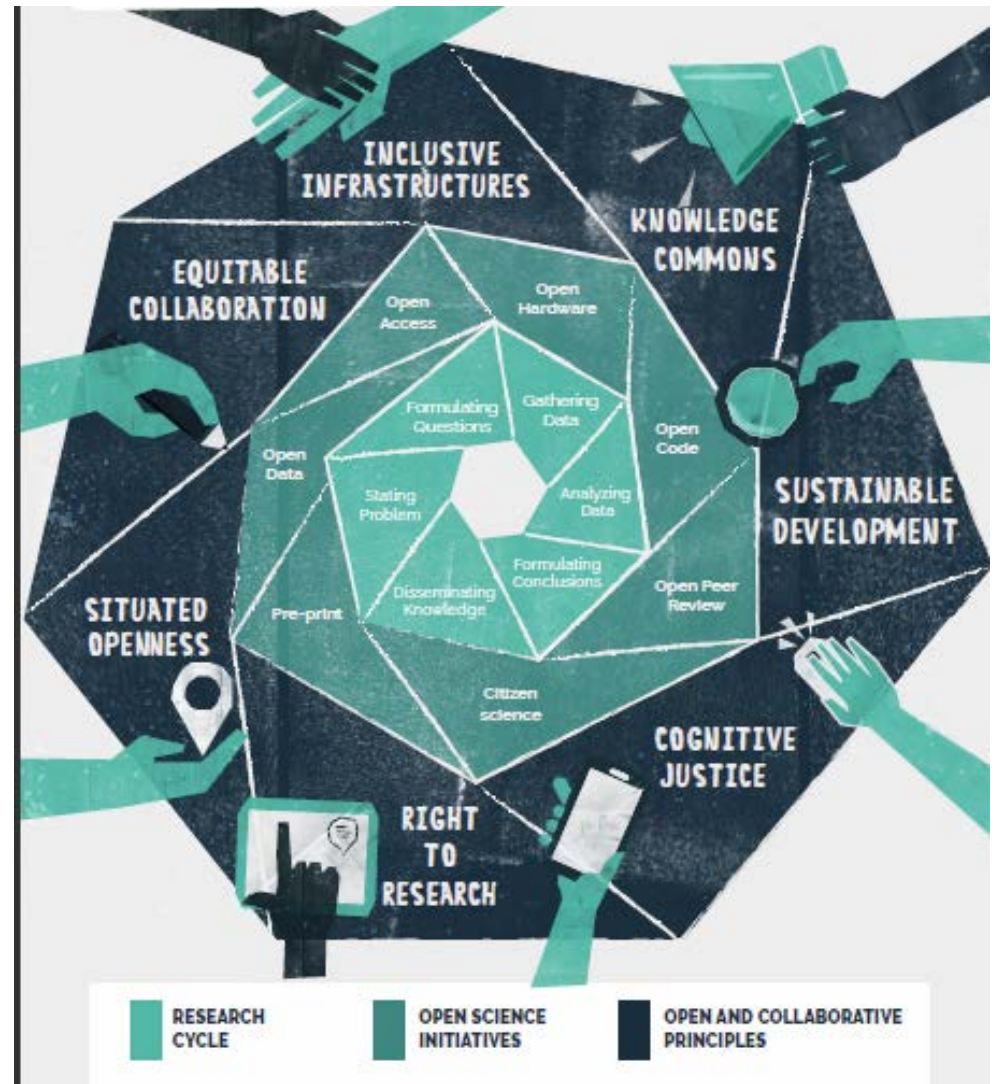




*There is no singular “right way” to do open science, and the process will always differ by context. We offer these seven principles as a foundation upon which to deliberate and realise a more inclusive notion of science in development.*



*La Red de Ciencia Abierta y Colaborativa para el Desarrollo (OCSDNet) se compone de doce equipos de investigación del Sur Global interesados en entender el rol de la apertura y colaboración en la Ciencia como una herramienta transformadora del pensamiento y practica del desarrollo.*



**Politiques....**

**El cas europeu vs open science**

Brussels, 27 May 2016  
(OR. en)

9526/16

RECH 208  
TELECOM 100

#### OUTCOME OF PROCEEDINGS

From:	General Secretariat of the Council
To:	Delegations
No. prev. doc.:	8791/16 RECH 133 TELECOM 74
Subject:	The transition towards an Open Science system - Council conclusions (adopted on 27/05/2016)



Science ministers from European Union nations AGREED last month to **make publicly funded research publications freely available by 2020**. Each country will implement its own publication policy.

#### The Council:

**UNDERLINES** the principle for the optimal reuse of research data should be: “**as open as possible, as closed as necessary**”.

**EMPHASIZED** that the opportunities for the optimal reuse of research data can only be realised if data are consistent with the FAIR principles (findable, accessible, interoperable and re-usable) within a secure and trustworthy environment

# Draft European Open Science Agenda. 26 February 2016

## Based on 5 policy actions:

- Foster Open Science
- Remove barriers to Open Science
- Develop research infrastructures for Open Science
- Mainstream Open Access to research results
- Embed Open Science in Society





## RESEARCH & INNOVATION

### Open Science

European Commission > Research & Innovation > Open Science > Open Science Policy Platform

Home Open Access European Open Science Cloud **Open Science Policy Platform** Expert Group on Altmetrics

## European Open Science Policy Platform

### Members of the OSPP

The Members of the Open Science Policy Platform (OSPP) have been nominated. Commissioner Maedas, during the 27 May Competitiveness Council, will announce the Members of the Platform and he will inform the Member States on the role of the Policy Platform in further developing a European Open Science Policy Agenda.

► [List of Nominated Members of the Open Science Policy Platform](#) 210 KB

### Relevant Documents

■ [List of Nominated Members of the Open Science Policy Platform](#) 210 KB

■ [Draft European Open Science Agenda](#) 124 KB

### About the OSPP

The Directorate-General for Research and Innovation will establish a Commission Expert Group to provide advice about the development and implementation of open science policy in Europe.



## Guidelines on Open Access to Scientific Publications and Research Data in Horizon 2020

Version 1.0  
11 December 2013



## RESEARCH & INNOVATION

### Open Science

European Commission > Research & Innovation > Open Science > European Open Science Cloud

Home Open Access **European Open Science Cloud** Open Science Policy Platform Expert Group on Altmetrics

## European Open Science Cloud

### 20 June 2016 – first draft report from the High Level Expert Group

The Commission High Level Expert Group on the European Open Science Cloud (HLEG EOSC) has drafted their first report, which the Commission will publish shortly after the summer.

Enquiries can be made directly to members of the HLEG EOSC and/or to the Commission at [RTD-EOSC@ec.europa.eu](mailto:RTD-EOSC@ec.europa.eu).

### 19 April 2016 – European Open Science Cloud



Giving a major boost to Open Science in Europe, the Commission today presented its blueprint for cloud-based services and world-class data infrastructure to ensure science, business and public services reap benefits of big data revolution.

By bolstering and interconnecting existing research

### Events

**26-27 September 2016, Seville, Spain** - Applied RDI – making innovation happen!

**22 November 2016, Central London, United Kingdom** - Next steps for Open Access and Open Data research policy

**8-10 February 2017, Vienna, Austria** - 1st HBP Student Conference

[See all events](#)

### Focus on past events

**4-5 April 2016, Amsterdam** - Open Science Conference



## RESEARCH & INNOVATION

### Infrastructures

European Commission > Research & Innovation > Research Infrastructures > ESFRI



### The ESFRI Roadmap 2016

The **ESFRI Roadmap 2016** identifies the new Research Infrastructures (RI) of pan-European interest corresponding to the long term needs of the European research communities, covering all scientific areas, regardless of possible location.



The 2016 Roadmap consists of 21 ESFRI Projects with a high degree of maturity - including 6 new Projects - and 29 ESFRI Landmarks - RIs that reached the implementation phase by the end of 2015.

The ESFRI Roadmap 2016 was launched on 10 March 2016, in Amsterdam. The event was organized under the **Dutch Presidency** by the Royal Netherlands Academy of Arts and Sciences (KNAW) in close cooperation with ESFRI, the European Commission and the Dutch Ministry of Education, Culture and Science. Discussions focussed on strategic roadmapping, long-term sustainability and the socio-economic impact of research infrastructures.

See Event [Agenda](#) and [Live Stream](#)

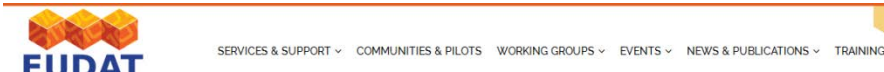
## ESFRI

### Highlights




An on-line map to locate the ESFRI infrastructures and their partner facilities. About 400 facilities are part of these distributed

# Servicios de apoyo a los investigadores ....




**EUDAT**  
SERVICES & SUPPORT ▾ COMMUNITIES & PILOTS ▾ WORKING GROUPS ▾ EVENTS ▾ NEWS & PUBLICATIONS ▾ TRAINING ▾


EUDAT: the collaborative Pan-European infrastructure providing research data services, training and consultancy for




Researchers




Research Communities




Research Infrastructures & Data Centres




**B2DROP**  
Sync and Exchange Research Data  
Read more! use




**B2SHARE**  
Store and Share Research Data  
Read more! use



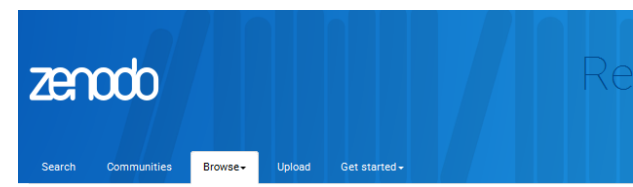
**B2SAFE**  
Replicate Research Data Safely  
Read more!



**B2STAGE**  
Get Data to Computation  
Read more!



**B2FIND**  
Find Research Data  
Read more! use



**zenodo**  
Search Communities Browse ▾ Upload Get started ▾

Datasets

Recent Uploads

23 March 2016 Dataset Open access

View

**Trophic-meta-analysis: First release of tritrophic meta-analysis data and code**  
Monica Granados

First release of data and code associated with "Interaction strength and the impact of introduced omnivores: A meta-analysis of introduced aquatic invasive species" manuscript

Uploaded by Monsaue on 23 March 2016.

22 March 2016 Dataset Open access

View

**Huntingtin linker sequence determination by computational methods - correspondence with Alex Holehouse**  
Holehouse, Alex; Pappu, Rohit; Harding, Rachel

Huntingtin open lab notebook project


Uploaded by rachejaneharding on 22 March 2016.

28 August 2014 Dataset Open access

View

**...**

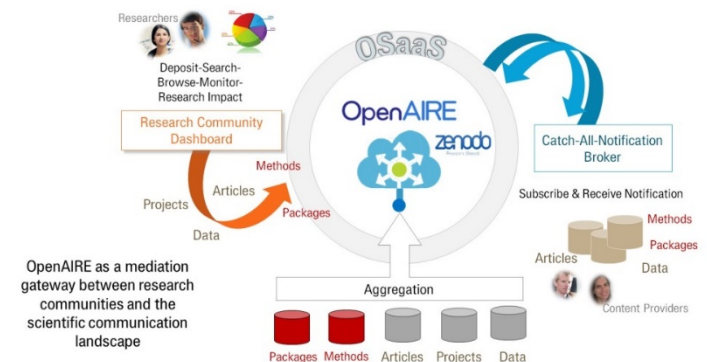
## OpenAIRE-Connect



**OpenAIRE**  
PARTICIPATE DEPOSIT, JOIN SEARCH PUBLICATIONS, DATA, PROJECTS STATISTICS QA, PROJECTS, TOPICS SUPPORT FAQ, HELPDESK, GUIDES OPEN ACCESS IN EUROPE

Science. Set free.

## Open Science as-a-Service (OSaaS)



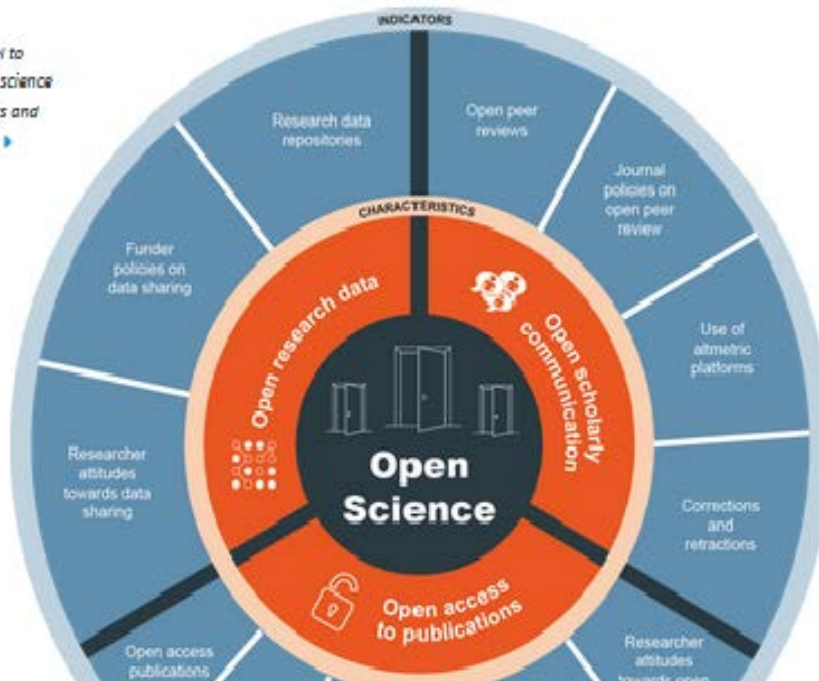


## Open Science Monitor

[Home](#) | [About](#) | [Open Access to Publications](#) | [Open Research Data](#) | [Open Scholarly Communication](#) | [Citizen Science](#) | [Drivers & Barriers](#)

Open science represents an approach to research that is collaborative, transparent and accessible. Open science occurs across the research process and there are many different activities that can be considered part of this evolution in science. The open science monitor tracks trends in areas that have consistent and reliable data.

Use the wheel to explore open science characteristics and indicators. >>





# “The European Open Science Cloud is a supporting environment for Open science and not an ‘open cloud’ for science”

Home

## E-INFRASTRUCTURES: MAKING EUROPE THE BEST PLACE FOR RESEARCH AND INNOVATION.

## A landmark agreement sustaining the pan European Collaborative Data Infrastructure for the next 10 years

3<sup>rd</sup> October 2016

16 major European research organisations, data and computing centres signed an agreement to sustain the EUDAT – pan European collaborative data infrastructure for the next 10 years. The organisations stand together behind a long term sustainability plan and commit to develop, maintain and deploy pan-European research data services and to promote harmonization of research data management practices across centres.



**What does this mean?**

Service providers, both generic and thematic, and research communities have joined forces as part of a common framework for developing an interoperable layer of common data services. Known as the EUDAT Collaborative Data Infrastructure (CDI), this is essentially a European e-infrastructure of integrated data services and resources to support research. This infrastructure and its services have been developed in close collaboration with over 50 research communities spanning across many different scientific disciplines and involved at all stage of the design process. The establishment of the EUDAT CDI is timely with the imminent realization of the European Open Science Cloud<sup>[1]</sup> which aims to offer open and seamless services for storage, management, analysis and re-use of research data, across borders and scientific disciplines.

### EUROPEAN OPEN SCIENCE CLOUD

BRINGING TOGETHER CURRENT AND FUTURE DATA INFRASTRUCTURES

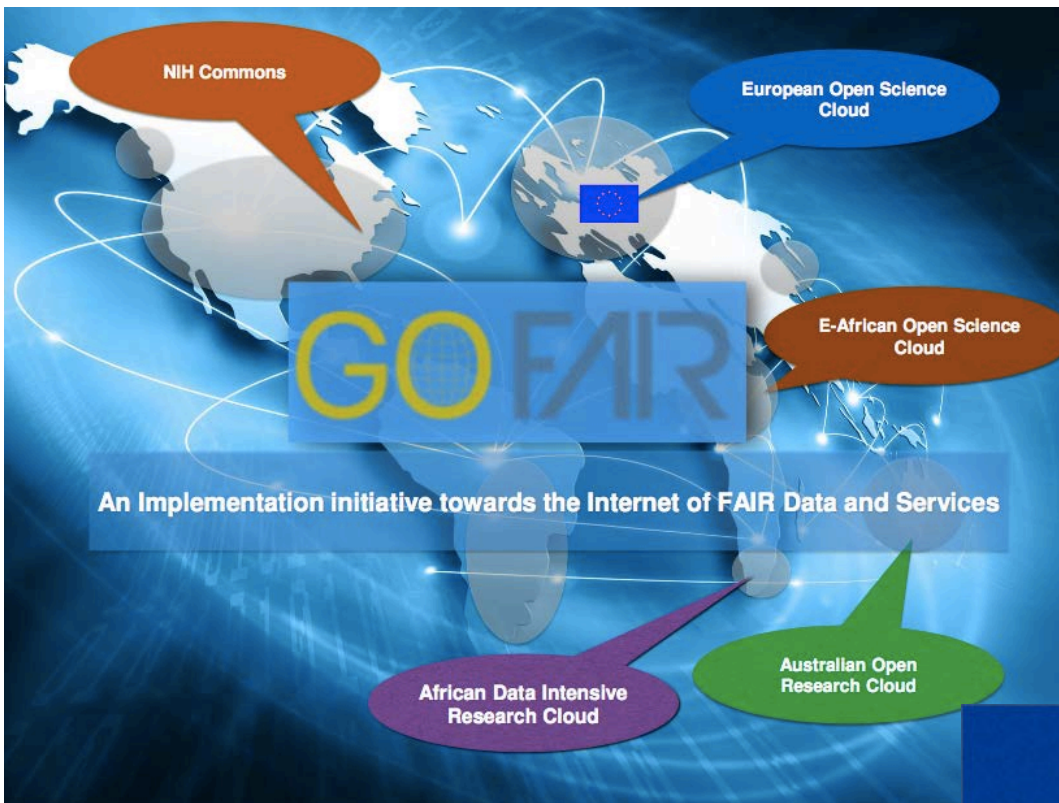
- A trusted, open environment for sharing scientific data
- Open and seamless services to analyse and reuse research data
- Linking data
- Connecting across borders and scientific disciplines
- Connecting scientists globally
- Long term and sustainable
- Improving science

### EUROPEAN DATA INFRASTRUCTURE

UNLOCKING THE VALUE OF BIG DATA; DIGITAL BY DEFAULT

- facilitate access to and re-use of data for researchers, innovators and public sector
- work in combination with national and regional, scientific and public data and computing centres
- reduce the cost of big data storage and high-performance analysis

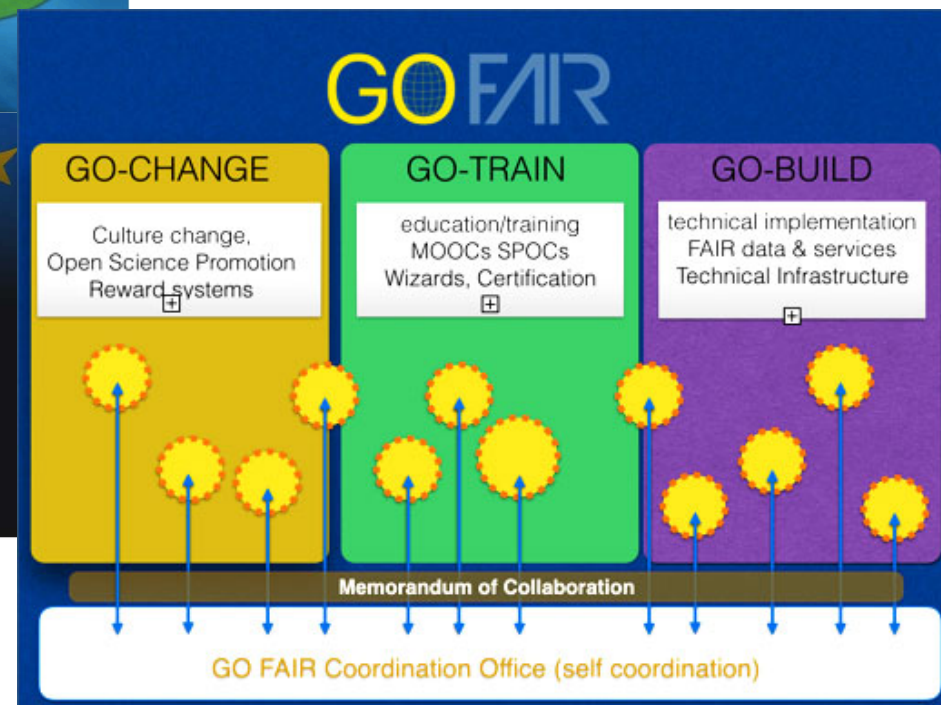




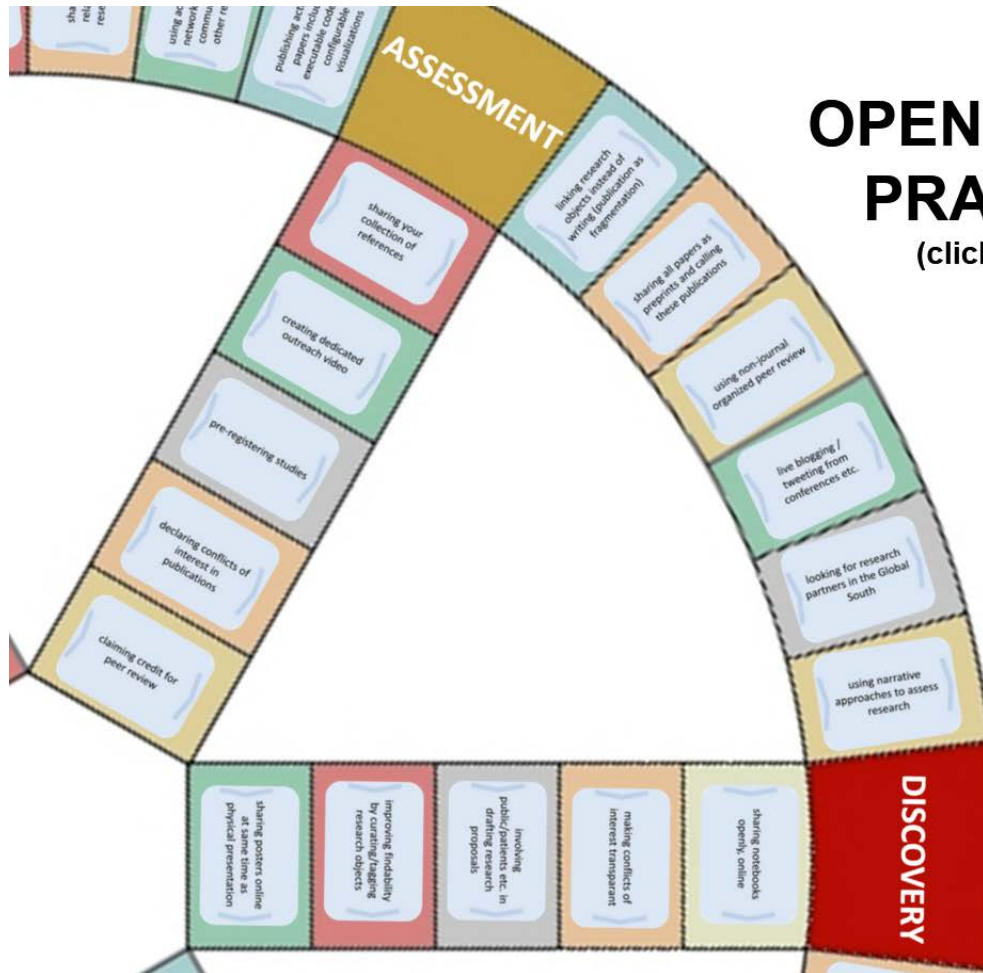
*"GO-FAIR" is a proposal for the practical implementation of the European Open Science Cloud (EOSC) through a federated approach making optimal use of existing initiatives and infrastructures in the participating Member States*

## GO-FAIR: A Member States-Up strategy for the EOSC implementation

"GO-FAIR" is a proposal for the practical implementation of the European Open Science Cloud (EOSC) through a federated approach making optimal use of existing initiatives and infrastructures in the participating Member States.



# **Altres iniciatives....**



Created with  
iSpring Converter Pro  
EVALUATION VERSION

# OPEN SCIENCE PRACTICES

(click to activate)



Jeroen Bosman / Bianca Kramer  
<http://101innovations.wordpress.com>

<https://bmkrater.databox.me/Public/Wheel of Open Science/>

# Participate in Open Science

COS collaborates with and produces tools for scientists, journals and societies, and developers. Below, explore ways to use our free services or collaborate on promoting open science.

[Ambassadors](#)[Scientists](#)[Journals and Societies](#)[Developers](#)

## Take Steps Towards Transparency

COS offers researchers tools and services to make your research better, more efficient, and more reproducible.

### 1. Use The Open Science Framework (OSF)

OSF is a free, secure web application for project management, collaboration, registration, and archiving. Stop losing files, improve collaboration, and integrate OSF projects with the tools you use (e.g., Dropbox, GitHub, Figshare, Dataverse). [Learn more.](#)



[Sign up for the OSF](#)

### 2. Conduct Reproducible Analyses

COS offers free statistical consulting to improve reproducible practices. Get email help on power analysis and calculating confidence intervals, individualized hangouts for learning R and GitHub, or schedule a group to be trained on OSF. [Read more.](#)



[Request a consultation](#)

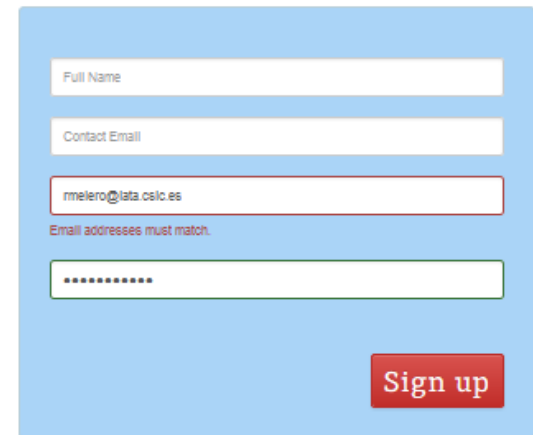
### 3. Pre-register your studies

[http://centerforopenscience.org/involved\\_participate/#tab\\_2](http://centerforopenscience.org/involved_participate/#tab_2)

# Open Science Framework <https://osf.io/>

Project management with  
collaborators,  
project sharing with the public

The Open Science Framework (OSF) supports the entire research lifecycle: planning, execution, reporting, archiving, and discovery.

A sign-up form on a light blue background. It contains four input fields: 'Full Name', 'Contact Email', a password field with the text 'meloero@ata.csic.es' and a red border, and a confirmation password field with asterisks. Below the password fields is the text 'Email addresses must match.' in red. A red 'Sign up' button is located at the bottom right of the form area.

Full Name

Contact Email

meloero@ata.csic.es

Email addresses must match.

\*\*\*\*\*

Sign up

## What can the OSF do for you?

Provide features to increase the efficiency and effectiveness of your research



### CONNECTIONS

with the services you already use

Link services to simplify transitions and facilitate interactions; e.g., connect OSF to your Dropbox, GitHub, and Amazon S3 repositories and all four work together!



### ARCHIVING

and managing collaborations

Spend more time doing your research and less time keeping track of it. No more lost data from crashed drives, disappearing collaborators, or failing memories.



### CONTROL

over private and public workflows

Work privately among collaborators and, when you wish, make some or all of your research materials public for others to use and cite.



▼ **FUNDING OPEN ACCESS**

▼ **RESEARCH PROMOTION**

▼ **OPEN ACCESS IN HUMANITIES**

**TAG ARCHIVES: FUNDING ▼**



February 13, 2015

**O & A on Open Access funding**

All stories were created by Agata Morka, Product Manager of Open Access Books...

[read more →](#)



February 4, 2015

**How to get your Article Processing Charges funded? – a step by step guide**

Publishers do not expect authors to pay for APC out of their own pocket, and...

[read more →](#)



November 25, 2014

**Bill and Melinda Gates Foundation, new Open Access Funder, especially for low and middle income countries**

Starting from January 1, 2015 all new funding agreements with the Bill and...

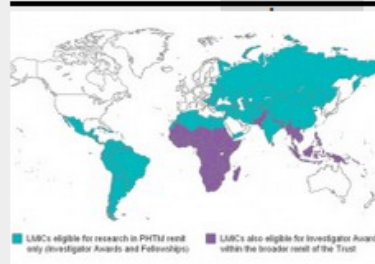
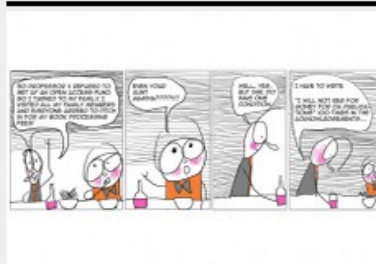


August 7, 2014

**Agata Morka on Open Access Book publishing and Emerging Scholar Monograph Competition**

Today I would like to present an interview with Dr. Agata Morka, Product...

[read more →](#)



# 101 INNOVATIONS IN SCHOLARLY COMMUNICATION

innoscholcomm.silk.co



Jeroen Bosman @jeroenbosman  
Utrecht University Library

## THE CHANGING RESEARCH WORKFLOW

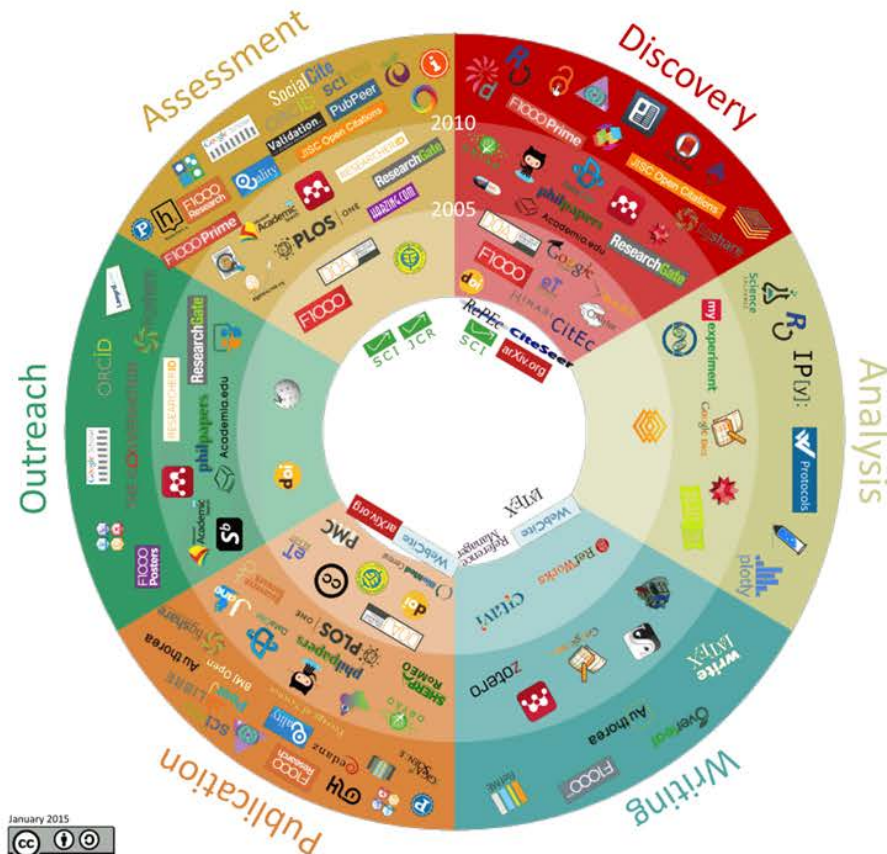


Bianca Kramer @MsPhelps  
Utrecht University Library

Science is in transition. This poster gives an impression of the exploratory phase of a project aiming to chart innovation in scholarly information and communication flows from evolutionary and network perspectives.

We intend to address the questions of what drives innovation and how these innovations change research workflows and may contribute to more **open, efficient and good science**.

### 101 Innovative tools and sites in 6 research workflow phases (< 2000 - 2015)



### Most important developments in 6 research workflow phases

	Discovery	Analysis	Writing	Publication	Outreach	Assessment
Trends	social discovery tools	datadriven & crowdsourced science	collaborative online writing	Open Access & data publication	scholarly social media	article level (alt)metrics
Expectations	growing importance of data discovery	more online analysis tools	more integration with publication & assessment tools	more use of "publish first, judge later"	use of altmetrics for monitoring outreach	more open and post-publication peer review
Uncertainties	support for full-text search and text mining	willingness to share in analysis phase	acceptance of collaborative online writing	effect of journal/publisher status	requirements of funders & institutions	who pays for costly qualitative assessment?
Opportunities	discovery based on aggregated OA full text	open labnotes	semantic tagging while writing/citing	reader-side paper formatting	using repositories for institutional visibility	using author-, publication- and affiliation-IDs
Challenges	real semantic search (concepts & relations)	reproducibility	safety/privacy of online writing	globalization of publishing/access standards	making outreach a two-way discussion	quality of measuring tools
Most important long-term development	multidisciplinary + citation-enhanced databases	collaboration + data-driven	online writing platforms	Open Access	more & better connected researcher profiles	importance of societal relevance + non-publication contributions
Potentially most disruptive development	semantic/concept search + contextual/social recommendations	open science	collaborative writing + integration with publishing	circumventing traditional publishers	public access to research findings, also for agenda setting	moving away from simple quantitative indicators

### Typical workflow examples



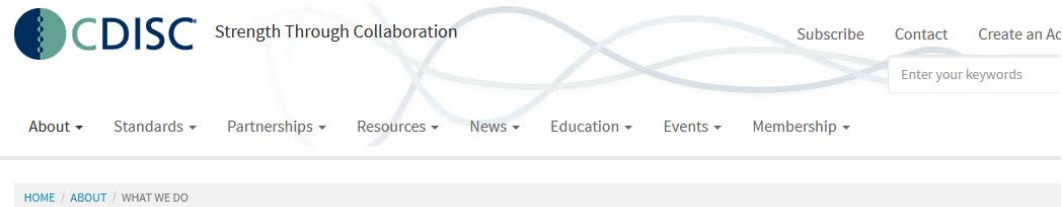
<https://101innovations.wordpress.com/>

[https://s3-eu-west-1.amazonaws.com/pfigshare-u-previews/1863601/page\\_1\\_width\\_2000.png](https://s3-eu-west-1.amazonaws.com/pfigshare-u-previews/1863601/page_1_width_2000.png)



<https://www.cdisc.org/about/what-we-do>

La importància dels estàndards en la interoperabilitat i el anàlisi de dades



## What We Do

### Introduction to CDISC

Unlocking cures is our life's work. At CDISC, we enable clinical research to work smarter by allowing data to speak the same language.



Clinical Data Interchange Standards Consortium







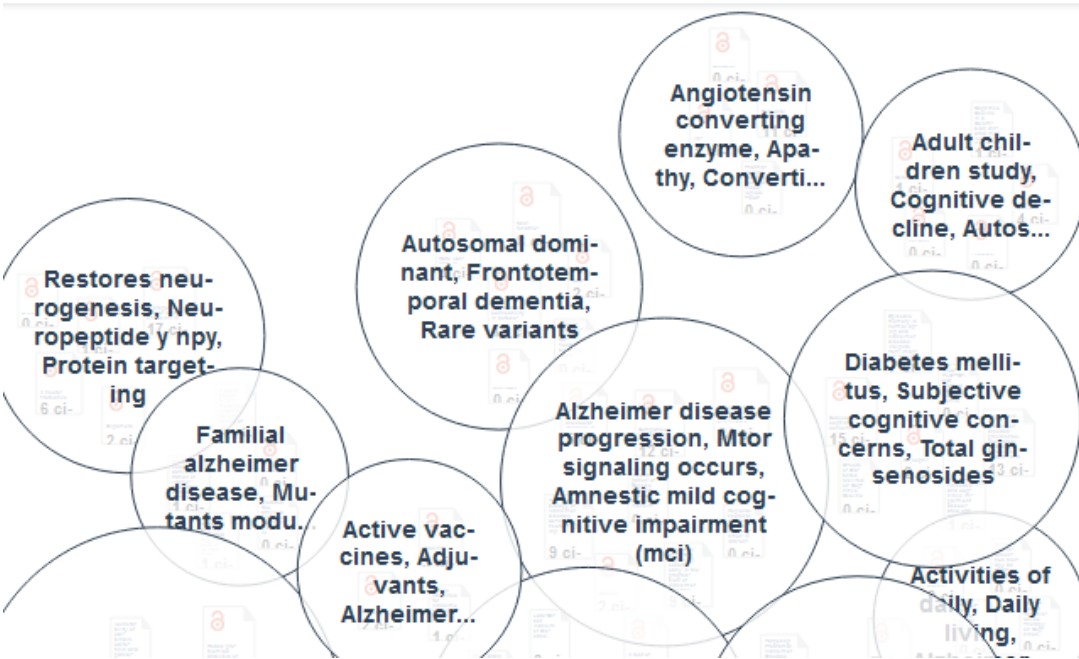
<https://openknowledgemaps.org/index.php>

beta version

## Visualize a research topic

Choose a library:

- ☐ PubMed (biomedicine) ⓘ
- ☒ BASE (all disciplines) ⓘ



### Mitochondrial defects and oxidative stress in Alzheimer disease and Parkinson disease. ⓘ

Michael H Yan, Xinglong Wang, Xiongwei Zhu in *Free radical biology & medicine* (2013)

Alzheimer disease (AD) and Parkinson disease (PD) are the two most common age-related neurodegenerative diseases characterized by prominent neurodegeneration in selective neural systems. Although a small fraction of AD and PD cases exhibit evidence o...

**Area:** Mitochondrial dna, Apoe4, Free radicals

### Variants in the ATP-binding cassette transporter (ABCA7), apolipoprotein E ε4, and the risk of late-onset Alzheimer disease in African Americans. ⓘ

Christiane Reitz, Gyungah Jun, Adam Naj, Ruchita Rajbhandary, Badri Narayan Vardarajan, Li-San Wang, Otto Valladares, Chiao-Feng Lin, Eric B Larson, Neill R Graff-Radford, Denis Evans, Philip L De Jager, Paul K Crane, Joseph D Buxbaum, Jill R Murrell, Towfique Raj, Nilufer Ertekin-Taner, Mark Logue, Clinton T Baldwin, Robert C Green, Lisa L Barnes, Laura B Cantwell, M Daniele Fallin, Rodney C P Go, Patrick Griffith, Thomas O Obisesan, Jennifer J Manly, Kathryn L Lunetta, M Ilyas Kamboh, Oscar L Lopez, David A Bennett, Hugh Hendrie, Kathleen S Hall, Alison M Goate, Goldie S Byrd, Walter A Kukull,

<http://genomicsandhealth.org/>



ABOUT GLOBAL ALLIANCE   WORKING GROUPS   PRODUCTS & PROJECTS   MEMBERSHIP   NEW

### Framework for Responsible Sharing of Genomic and Health-Related Data

Read the Framework guided by human rights that offers foundational principles and core elements to facilitate responsible research conduct.

[Read Framework here](#)

## Our Work

The diverse members of the Global Alliance for Genomics and Health are working together to create interoperable approaches to catalyze projects that will help unlock the great potential of genomic data. Our four **Working Groups** advance **Initiatives** that develop key **Work Products**.



### Clinical »

Aims to enable compatible, readily accessible, and scalable approaches for sharing clinical data and linking it with genomic data.



### Data »

Concentrates on data representation, storage, and analysis of genomic data to develop approaches that facilitate interoperability.



### Regulatory and Ethics »

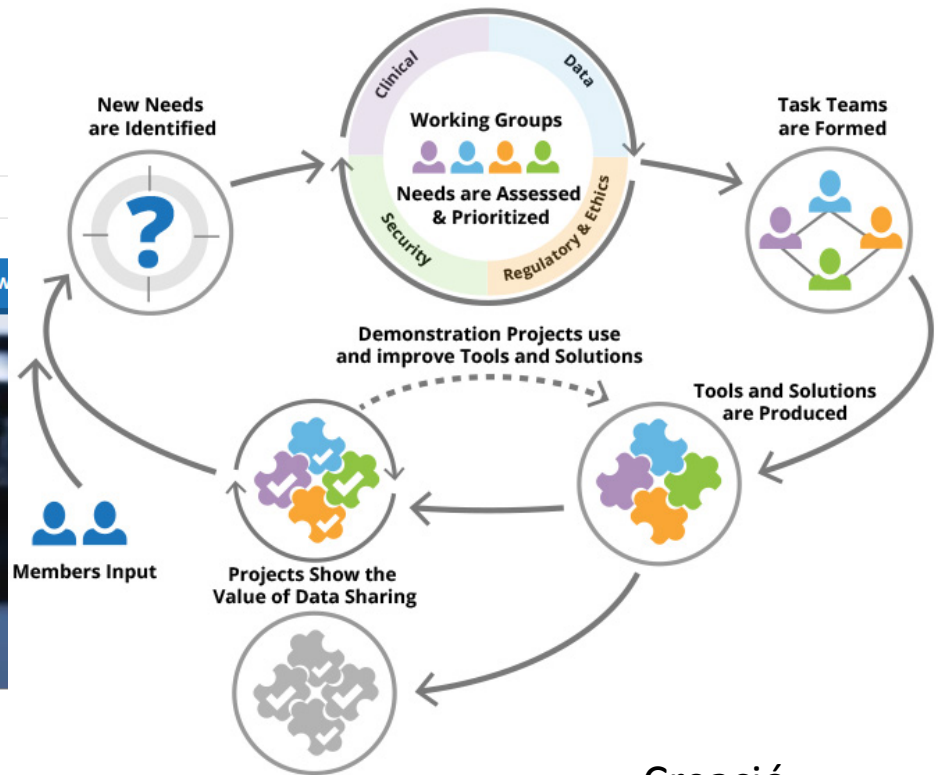
Focuses on ethics and the legal and social implications of the Global Alliance, including harmonizing policies and standards.



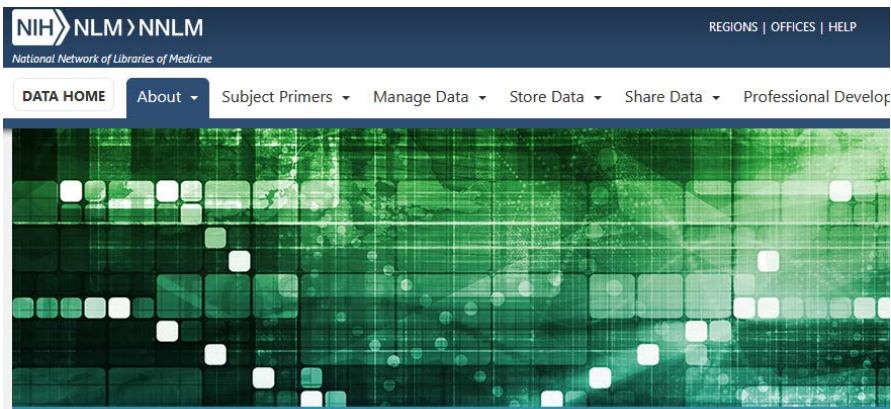
### Security »

Leads the thinking on the technology aspects of data security, user access control, audit functions, and developing or adopting data security standards.

## Recursos



Creació  
Necessitats



## Getting Started

### About NNLM RD3: Resources for Data-Driven Discovery

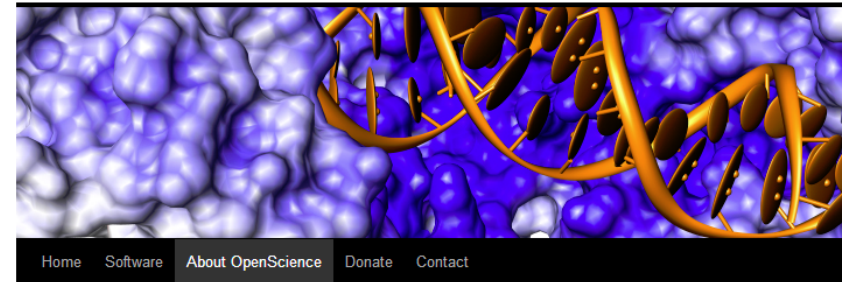
NNLM RD3 has been developed to foster learning and collaboration in data science. It is a collaborative project devoted to educating science and medical librarians. Content for NNLM RD3 is contributed by a dedicated team of subject specialists from diverse regional research libraries. We encourage your involvement in NNLM RD3 through comments, discussions, and content contributions.

If you have comments, suggestions, or ideas for content, please contact your [regional data coordinator](#)!

**NNLM RD3: Resources for Data-Driven Discovery Scope Statement:** NNLM RD3 is a resource for librarians, library students, information professionals, and interested individuals to learn about and discuss:

- Library roles in data science
- Fundamentals of domain sciences
- Emerging trends in supporting networked scientific research

## The OpenScience Project



### About OpenScience

*The OpenScience project* is dedicated to writing and releasing free and [Open Source](#) scientific software. We are a group of scientists, mathematicians and engineers who want to encourage a collaborative environment in which science can be pursued by *anyone* who is inspired to discover something new about the natural world.

Much of the work of science depends on having appropriate tools available to analyze experimental data and to interact with theoretical models. Powerful computers are now cheap enough so that significant processing power is within reach of many people. The missing piece of the puzzle is software that lets the scientist choose between models and make sense of his or her observations. That is where *the OpenScience project* can help.

Recursos per a la formació de biblioteques mediques  
*National Network of Libraries of Medicine (NNLM) is to advance the **progress of medicine and improve the public health** by providing all U.S. health professionals with **equal access to biomedical information and improving the public's access to information** to enable them to make informed decisions about their health.*

Desenvolupament  
open source

Formació

**Registre de casos clínicos un  
“open” molt important!**





# The NEW ENGLAND JOURNAL of MEDICINE

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## EDITORIAL

### Sharing Clinical Trial Data — A Proposal from the International Committee of Medical Journal Editors

Darren B. Taichman, M.D., Ph.D., Joyce Backus, M.S.L.S., Christopher Baethge, M.D., Howard Bauchner, M.D., Peter W. de Leeuw, M.D., Jeffrey M. Drazen, M.D., John Fletcher, M.B., B.Chir., M.P.H., Frank A. Frizelle, M.B., Ch.B., F.R.A.C.S., Trish Groves, M.B., B.S., M.R.C.Psych., Abraham Haileamlak, M.D., Astrid James, M.B., B.S., Christine Laine, M.D., M.P.H., Larry Peiperl, M.D., Anja Pinborg, M.D., Peush Sahni, M.B., B.S., M.S., Ph.D., and Sinan Wu, M.D.  
N Engl J Med 2016; 374:384–386 | [January 28, 2016](#) | DOI: 10.1056/NEJMe1515172

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[Article](#)[References](#)[Citing Articles \(16\)](#)[Letters](#)[Metrics](#)

The International Committee of Medical Journal Editors (ICMJE) believes that there is an ethical obligation to responsibly share data generated by interventional clinical trials because participants have put themselves at risk. In a growing consensus, many funders around the world — foundations, government agencies, and industry — now mandate data sharing. Here we outline the ICMJE's proposed requirements to help meet this obligation. We encourage feedback on the proposed requirements. Anyone can provide feedback at [www.icmje.org](http://www.icmje.org) by 18 April 2016.

The ICMJE defines a clinical trial as any research project that prospectively assigns people or a group of people to an intervention, with or without concurrent comparison or control groups, to study the cause-and-effect relationship between a health-related intervention and a health outcome. Further details may be found in the *Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals* at [www.icmje.org](http://www.icmje.org).

The ICMJE **proposes to require authors to share with others the de-identified individual-patient data (IPD) underlying the results** presented in the article no later than 6 months after publication.

Sharing clinical trial data, including de-identified IPD, requires planning to ensure appropriate ethics committee or institutional review board approval and the informed consent of study participants.

 Search[House of Delegates](#) [Physicians](#) [Residents](#) [Medical Students](#) [Patients](#) [Media](#)[Home](#) [Membership](#) [Resources](#) [Education](#) [Advocacy](#) [Publications](#) [News](#) [AMA Store](#) [About AMA](#)[News » 2016 AMA Press Releases and Statements » American Medical Association Joins AllTrials Campaign for Clinical Trial Transparency](#)

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## AMA News Room

Search News

[2016](#) [2015](#) [2014](#)

March 17, 2016

## American Medical Association Joins AllTrials Campaign for Clinical Trial Transparency

For immediate release:

March 17, 2016

*The AMA strongly supports improving the timeliness and accessibility of clinical trial data to reduce the duplication of research and help inform future research—ultimately improving health outcomes for patients," said AMA President Steven. J. Stack. "The AMA is pleased to join the AllTrials initiative to continue efforts aimed at ensuring open access to clinical trial data for physicians, researchers and patients.*

Around half of clinical trials have never been reported.  
This is the story of the campaign to find them—  
and to fix medicine.

Read the AllTrials story

## COMPARE

TRACKING SWITCHED OUTCOMES IN CLINICAL TRIALS

METHODS | RESULTS | TEAM | FAQ

1. We compared each clinical trial report with its protocol or registry entry. Some trials reported their outcomes perfectly. For the others, we counted how many of the outcomes pre-specified in the protocol or registry were never reported. We also counted how many new outcomes were silently added.
2. When we detected unreported or added outcomes, we wrote a letter to the journal pointing them out. We tracked which journals published our letters – and which did not.

Here's what we found.

67

TRIALS CHECKED

9

TRIALS WERE PERFECT

354

OUTCOMES NOT  
REPORTED

357

NEW OUTCOMES  
SILENTLY ADDED

On average, each trial reported just 58.2% of its specified outcomes. And on average, each trial silently added 5.3 new outcomes.

58

LETTERS SENT

18

LETTERS PUBLISHED

8

LETTERS  
UNPUBLISHED AFTER 4  
WEEKS

32

LETTERS REJECTED BY  
EDITOR

<http://compare-trials.org/>

Compare Tracking switched outcomes in clinical trials [Seguiment dels resultats en els assajos clínics]

## Clinical Trial Registration

The ICMJE's clinical trial registration policy is detailed in a series of editorials (see [Updates and Editorials](#) and [FAQs](#)).

Briefly, the ICMJE requires, and recommends that all medical journal editors require, registration of clinical trials in a public trials registry at or before the time of first patient enrollment as a condition of consideration for publication. Editors requesting inclusion of their journal on the ICMJE website [list of publications](#) that follow ICMJE guidance should recognize that the listing implies enforcement by the journal of ICMJE's trial registration policy.

The ICMJE defines a clinical trial as any research project that prospectively assigns people or a group of people to an intervention, with or without concurrent comparison or control groups, to study the cause-and-effect relationship between a health-related intervention *and* a health outcome. Health-related interventions are those used to modify a biomedical or health-related outcome; examples include drugs, surgical procedures, devices, behavioural treatments, educational programs, dietary interventions, quality improvement interventions, and process-of-care changes. Health outcomes are any biomedical or health-related measures obtained in patients or participants, including pharmacokinetic measures and adverse events. The ICMJE does not define the timing of first patient enrollment, but best practice dictates registration by the time of first patient consent.

**OpenTrials** is a collaboration between [Open Knowledge International](#) and Dr Ben Goldacre from the University of Oxford [DataLab](#). It aims to locate, match, and share all publicly accessible data and documents, on all trials conducted, on all medicines and other treatments, globally. To find out more read [this paper](#).

Explore the **public beta version** of OpenTrials [here](#).

Find trial by title, identifier or other keywords (e.g. "heart attack")



Advanced search

▶ Intro video

The screenshot shows the OpenTrials website interface. At the top, there's a navigation bar with links: About, Patients, Researchers, Transparency, and a Login/Register button. Below the navigation bar, the main heading reads "For researchers" followed by the title "Mertrazine and Cobazol to Treat Major Depression". There's a "XSL" button next to the title. Below the title, it says "OpenTrials > For Researchers > Depression > Mertrazine and Cobazol". The "Overview" section shows details: Condition: Major Depression, Treatment: Mertrazine, Cobazol, Date: June 2004 - March 2010. It also lists "Participants", "Men and women", and "Aged 18-65". Below the overview, there are three columns: "Registries" (ClinicalTrials.gov, BioMed Inc, Add another), "Regulatory documents" (CSR, EPAR segment, Add another), and "Paperwork" (Blank consent form, Patient information sheet, Blank case report form).



# Joint statement on public disclosure of results from clinical trials

## Signatories on 18 May 2017

Indian Council of Medical Research

Research Council of Norway

UK Medical Research Council

Médecins Sans Frontières

Epicentre

CEPI

PATH

Institut Pasteur

Bill and Melinda Gates Foundation

Wellcome Trust

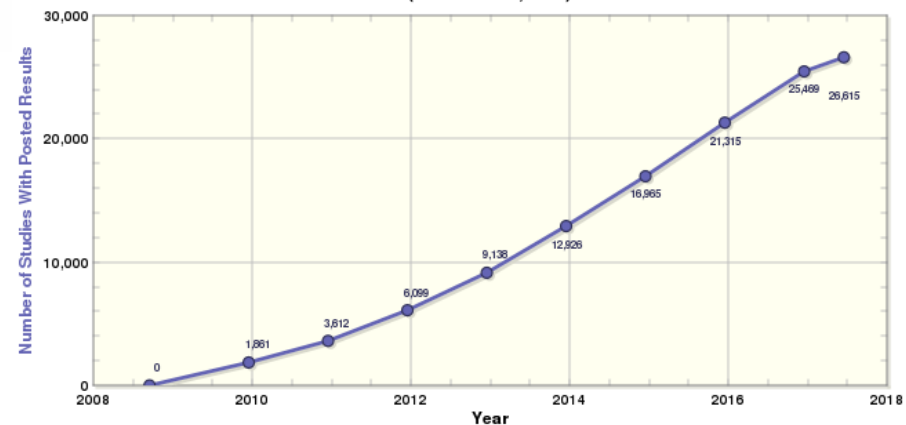
*The signatories of this joint statement affirm that the prospective registration and timely public disclosure of results from all clinical trials is of critical scientific and ethical importance. Furthermore **timely results disclosure reduces waste in research, increases value and efficiency in use of funds and reduces reporting bias, which should lead to better decision-making in health.***

Number of Registered Studies Over Time  
and Some Significant Events (as of June 01, 2017)



Source: <https://ClinicalTrials.gov>

Number of Registered Studies With Posted Results Over Time  
(as of June 01, 2017)



Source: <https://ClinicalTrials.gov>

<https://clinicaltrials.gov/ct2/resources/trends>

**Altres  
projectes.....**

<https://biosharing.org/>

<http://www.elixir-uk.org/>

<https://www.elixir-europe.org/>



ELIXIR unites Europe's leading life science organisations in managing and safeguarding the increasing volume of data being generated by publicly funded research. It coordinates, integrates and sustains bioinformatics resources across its member states and enables users in academia and industry to access services that are vital for their research. See [About us](#).



### Services

ELIXIR services make it easier to discover, store, and analyse life science data.



### Platforms

ELIXIR's activities are divided into five areas called 'Platforms'.



### EU Projects

ELIXIR both collaborates in and coordinates EU projects.



### Use Cases

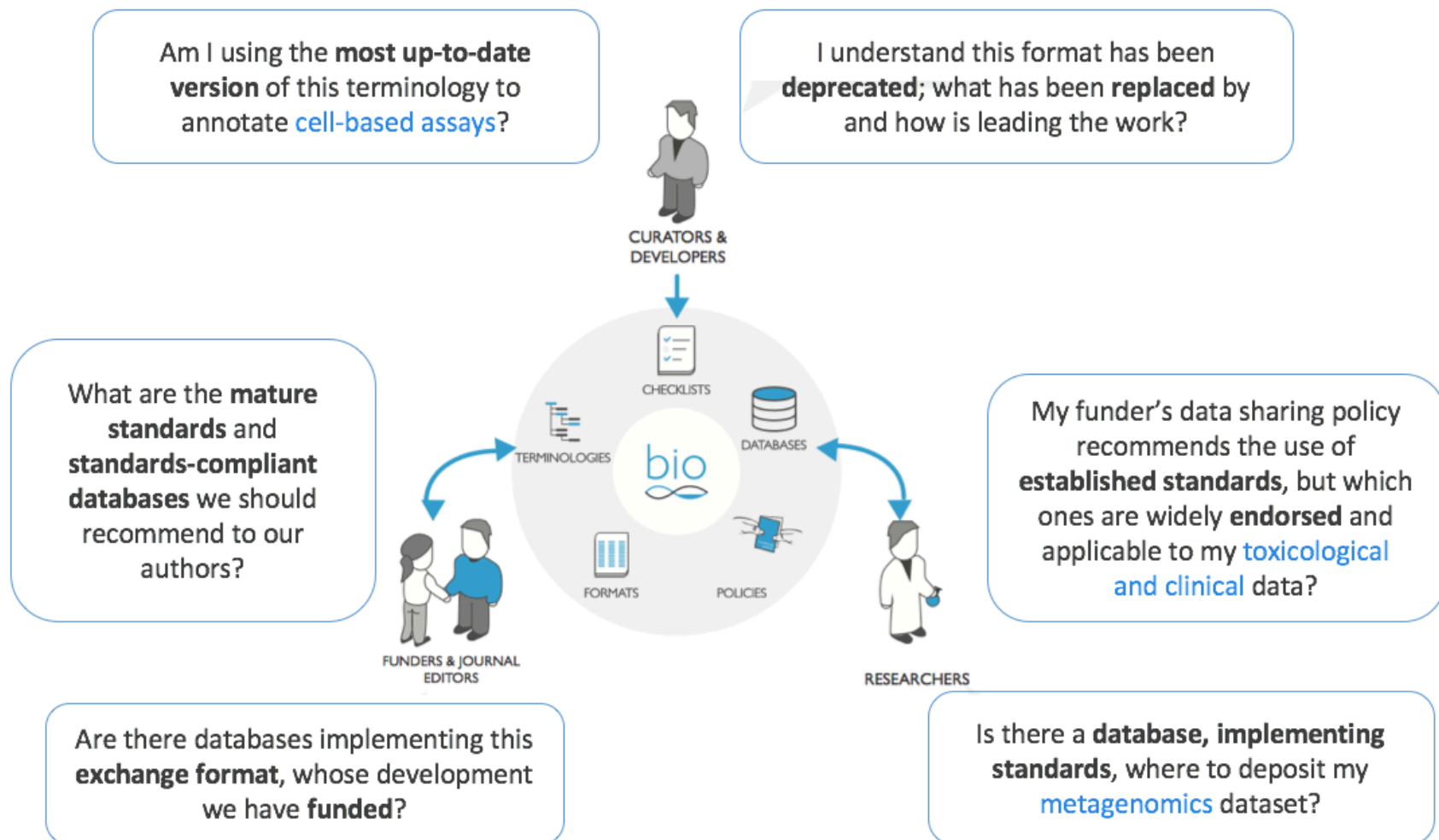
Use Cases develop services that are specialised for particular life science domains.

## Services:


[BioSharing](#) for community standards.

[bio.tools](#) for life science tools and data services.

[TeSS](#) for life science training courses and materials.




https://biosharing.org/

**biosharing.org** standards, databases, policies 


[Standards](#) [Databases](#) [Policies](#) [Collections](#) [Add/Claim Content](#) [Stats](#) [Log in or Register](#)

**Find**

 **Recommendations**


Standards and/or databases recommended by journal or funder data policies.

**Discover**

 **Collections**

Standards and/or databases grouped by domain, species or organization.

**Learn**


 **Educational**

About standards, their use in databases and policies, and how we can help you.

[Search](#)


☒ Standards ☒ Databases ☒ Policies ☒ Collections/Recommendations

**Advanced Search**




Fine grained control over your search.


**Search Wizard**

 **ask biosharing**


Let us guide you to your results.

 **666 Standards**

Terminology Artifact	346
Model/Format	210
Reporting Guideline	110

 **811 Databases**

Protein	163
Genome	126
DNA	84

 **81 Policies**

Funder	19
Journal	56
Society	2

Recursos sobre estándares, repositorios de datos, y recursos de formación en ciencias de la vida, medio ambiente y ciencias biomédicas

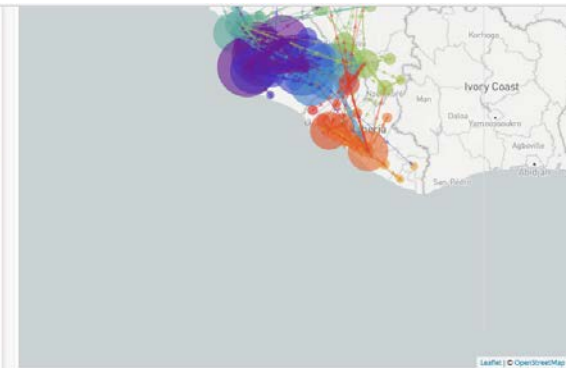
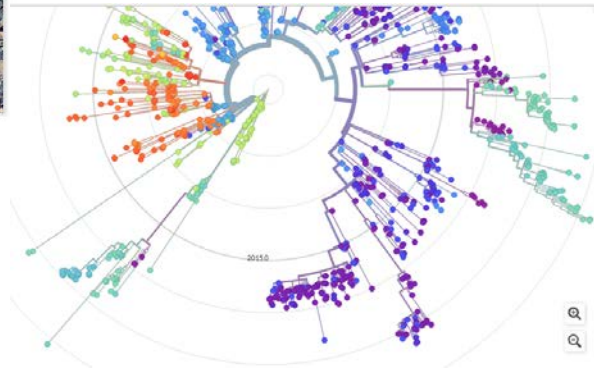
## Real-time tracking of virus evolution

Nextstrain is an open-source project to harness the scientific and public health potential of pathogen genome data. We provide a continually-updated view of publicly available data with powerful analytics and visualizations showing pathogen evolution and epidemic spread. Our goal is to aid epidemiological understanding and improve outbreak response.

[READ MORE](#)

## Ciència “colaborativa”

### Explore viruses



### 28th February 2017: nextstrain.org wins Open Science Prize!

Congratulations to Trevor Bedford, Richard Neher and their team, who win the grand prize of \$230,000. The Open Science Prize is a collaboration between the Wellcome Trust, the US National Institutes of Health (NIH) and the Howard Hughes Medical Institute to unleash the power of open content and data to advance biomedical research and its application for health benefit.

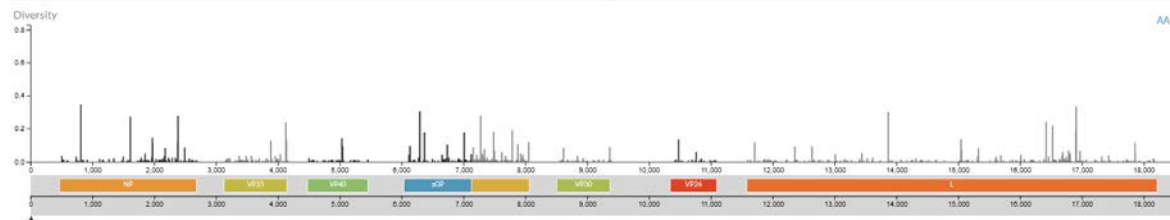
#### The winners



Real-Time Evolutionary Tracking for Pathogen Surveillance and Epidemiological Investigation

Try out the prototype: [nextstrain.org](http://nextstrain.org)

The goal of this project is to promote open sharing of viral genomic data and harness this data to make epidemiologically actionable inferences. The team will develop an integrated framework for real-time molecular epidemiology and evolutionary analysis of emerging epidemics, such as Ebola virus, MERS-CoV and Zika virus. The project will use an online visualization platform where the outputs of statistical analyses can be used by public health officials for epidemiological insights within days of samples being taken from patients.



This work is made possible by the open sharing of genetic data by research groups from all over the world. We gratefully acknowledge their contributions. For data reuse (particularly for publication), please contact the original authors: Albarino et al., Arlas et al., Balze et al., Bell et al., Capobianchi et al., Carroll et al., Castilletti et al., Gire et al., Goba et al., Hoenen et al., Kugelman et al., Ladner et al., Lewandowski et al., Quicke et al., Schibler et al., Simon-Loriere et al., Smits et al., Tong et al., Whitmer et al.





<http://www.reactome.org/>

Eines per la visualització,  
de estructures, anàlisi..

Browse Pathways

Analyze Data

Reactome FIViz app

User Guide

Data Download

Contact Us

**About Reactome**

Reactome is a free, open-source, curated and peer reviewed pathway database. Our goal is to provide intuitive bioinformatics tools for the visualization, interpretation and analysis of pathway knowledge to support basic research, genome analysis, modeling, systems biology and education. The current version (v58) of Reactome was released on October 5, 2016.



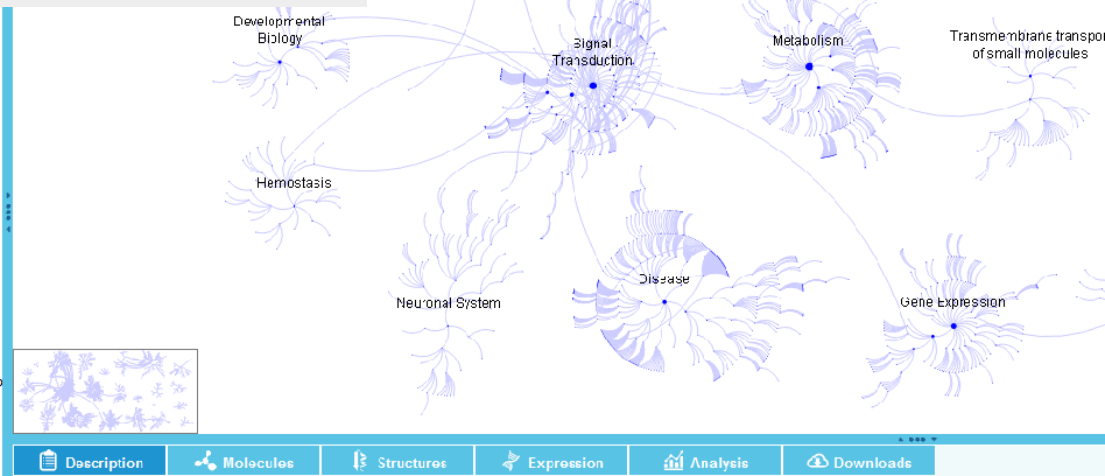
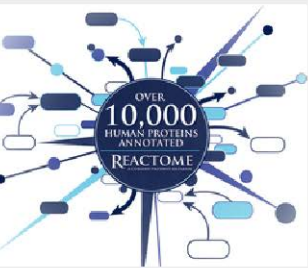
- Extracellular matrix organization
- Gene Expression
- Hemostasis
- Immune System
- Mitophagy
- Metabolism
- Metabolism of proteins
- Muscle contraction
- Neuronal System
- Organelle biogenesis and maintenance
- Programmed Cell Death
- Reproduction
- Signal Transduction
- Transmembrane transport of small molecules
- Vesicle-mediated transport

**Tweets**

**Current Version: Reactome V58**

reactome  
@reactome

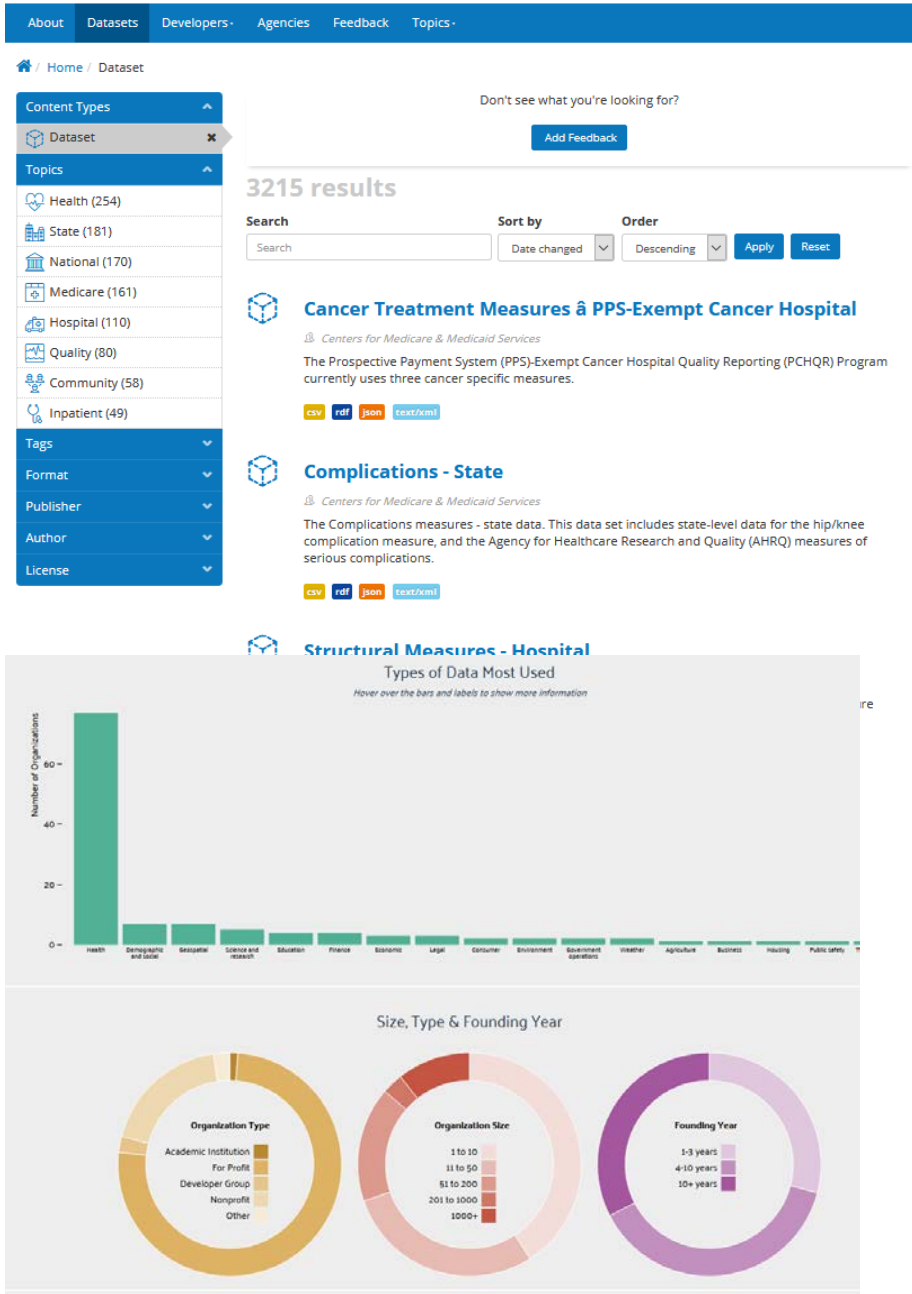
Our project achieves major milestone: annotation & release of its 10,000th human protein #oicr\_news #embl\_ebi #NYULMC #usereactome



Description   Molecules   Structures   Expression   Analysis   Downloads



Displays details when you select an item in the Pathway Browser. For example, when a reaction is selected, shows details including the input and output molecules, summary and references containing supporting evidence. When relevant, shows details of the catalyst, regulators, preceding and following events.



## Welcome to HealthData.gov

This site is dedicated to making high value health data more accessible to entrepreneurs, researchers, and policy makers in the hopes of better health outcomes for all.

Learn More



Ús dels open data (gov)  
Cas d'estudi: health

<http://www.opendataimpactmap.org/health.html#visualizations>



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[RESEARCH\\*EU MAGAZINES](#)
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 Booklet
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## ORION, a new European initiative to open up science to society

Contributed by: [Centre for Genomic Regulation \(CRG\)](#)

*ORION is a new collaborative European project to explore ways in which research and funding organizations in life sciences and biomedicine can open up the way they fund, organize and do research. The Centre for Genomic Regulation in Barcelona, Spain, coordinates this project and is one of the nine partners in the project. ORION kicks off in Barcelona this week.*

Open science is a core strategy of the European Commission that involves widening participation and collaboration as well as sharing research processes and outcomes to improve research and innovation. All European Union members recognise the benefits of open science, but the transition to "openness" is challenging.

Interesting challenges

The ORION project will help research and funding organizations to understand existing challenges in Open Science and implement institutional, cultural, and behavioral changes in how they carry out and manage research.



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CRG in the Media

Publications

### ARCHIVE

- 2017 (18)
- 2016 (56)
- 2015 (51)
- 2014 (43)
- 2013 (56)
- 2012 (48)
- 2011 (55)
- 2010 (40)
- 2009 (21)
- 2008 (18)

1 2 next » last »

## NEWS

09 Tue, 09/05/2017 - 12:30  
May

CRG coordinates ORION, a new European initiative to open up research to society



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Open science is a core strategy of the European Commission that involves widening participation and collaboration as well as sharing research processes and outcomes to improve research and innovation. All European Union members recognise the benefits of open science, but the transition to "openness" is challenging.

Ciència ciutadana

## AS OPEN AS POSSIBLE, AS CLOSED AS NECESSARY

Grantees have the right to **opt-out**, but need to say **why**



Top three reasons for **opt-out**:



The approach has been tested during a Horizon 2020 pilot action

2015

of 431 signed projects



65.4%

opted to share data

from 2017

the current  
Open Research Data Pilot  
expands to cover all areas of  
Horizon 2020,  
with the same rules

Horizon 2020 already mandates open access to all scientific publications



From 2017,  
research data is  
**open by default**,  
with possibilities to **opt out**

[https://ec.europa.eu/research/press/2016/pdf/opendata-infographic\\_072016.pdf](https://ec.europa.eu/research/press/2016/pdf/opendata-infographic_072016.pdf)



REGLAMENTO (UE) 2016/679 DEL PARLAMENTO EUROPEO Y DEL CONSEJO  
de 27 de abril de 2016 relativo a la protección de las personas físicas en lo que respecta  
al tratamiento de datos personales y a la libre circulación de estos datos y por el que se  
deroga la Directiva 95/46/CE (Reglamento general de protección de datos)

Entra en vigor en mayo del 2018

<http://eur-lex.europa.eu/legal-content/ES/TXT/HTML/?uri=CELEX:32016R0679&from=ES>


- Dret a la protecció de les pròpies dades
- Consentiment per al seu tractament
- Anonimització (suficient?)

Artículo 5 (Punto 1 letra a) Principios relativos al tratamiento

1. Los datos personales serán:

a) **tratados de manera lícita, leal y transparente en relación con el interesado («licitud, lealtad y transparencia»);**





# UTD ANONYMIZATION TOOLBOX

*.....privacy does matter*

## Main Menu

- Home
- Download
- Documentation
- FAQ
- UTD DSP Lab
- News
- Contact

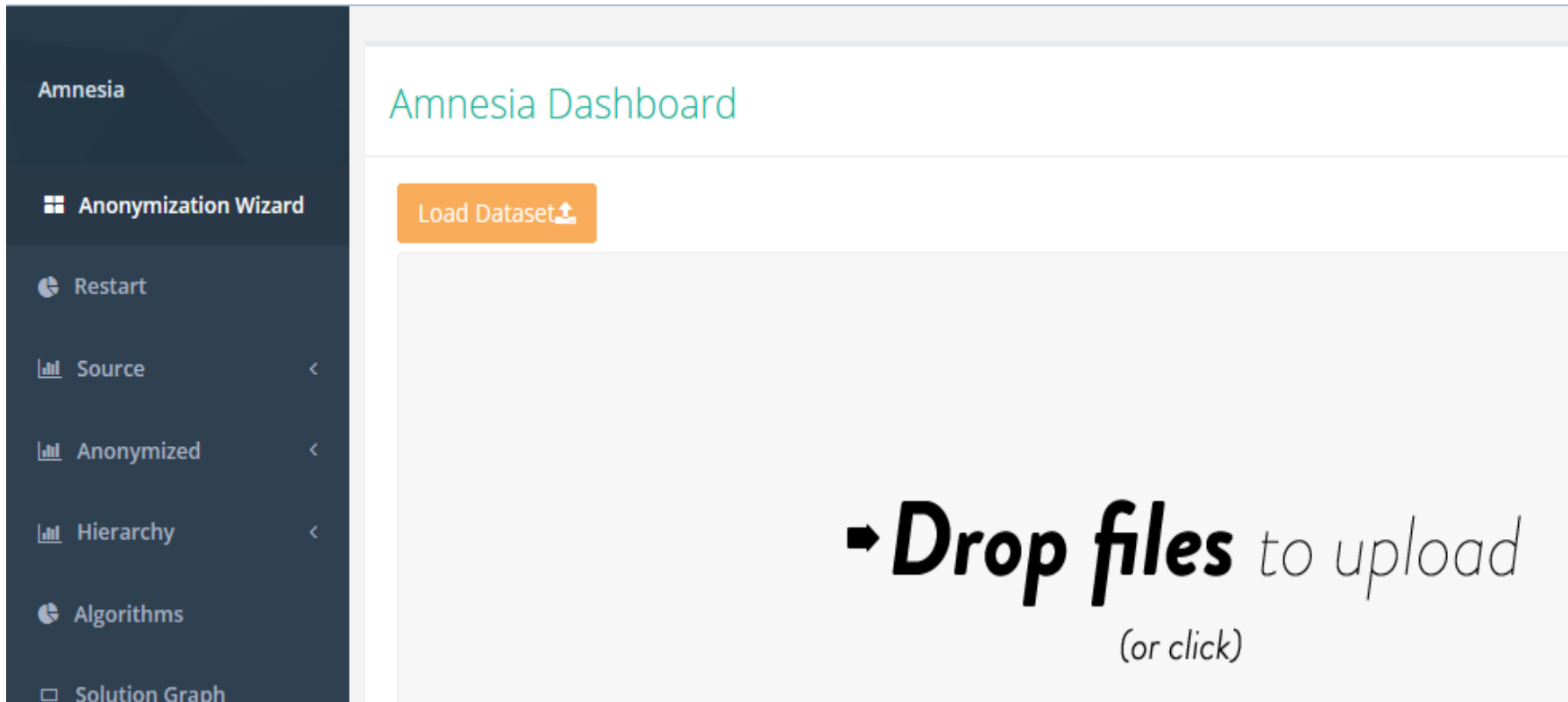
## Anonymization ToolBox

In an effort to promote our research in the area of privacy preserving data analysis, at UT Dallas Data Security and Privacy Lab, we compiled our implementation of various anonymization methods into a toolbox for public use by researchers. The algorithms can either be applied directly to a dataset or can be used as library functions inside other applications.

The toolbox currently contains 6 different anonymization methods over 3 different privacy definitions:

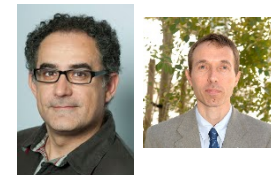
- Datafly
- Mondrian Multidimensional k-Anonymity
- Incognito
- Incognito with l-diversity
- Incognito with t-closeness
- Anatomy

<http://amnesia.imis.athena-innovation.gr:8080/amnesia/>



The screenshot shows the Amnesia Dashboard. On the left is a dark sidebar with the following menu items: 'Amnesia' (logo), 'Anonymization Wizard' (with a grid icon), 'Restart' (with a circular arrow icon), 'Source' (with a bar chart icon and a right arrow), 'Anonymized' (with a bar chart icon and a right arrow), 'Hierarchy' (with a bar chart icon and a right arrow), 'Algorithms' (with a circular arrow icon), and 'Solution Graph' (with a square icon). The main content area has a light gray background. At the top, it says 'Amnesia Dashboard' in teal. Below that is an orange button labeled 'Load Dataset' with an upload icon. The center of the dashboard features a large, stylized instruction: '➡ **Drop files** to upload (or click)'.

Continuen....



## 23 Cosas: Bibliotecas para los Datos de Investigación

Recursos prácticos y herramientas online libres, que puedes usar ya, para incorporar la Gestión de Datos de Investigación a tu práctica bibliotecaria

Compartir datos de investigación sin barreras

### Recursos de aprendizaje

Los bibliotecarios buscan y aprenden cómo aplicar los principios de la Biblioteconomía para dar nuevos servicios y solucionar problemas relacionados con los datos de investigación.

1. Las 10 recomendaciones más importantes de LIBER para empezar con la gestión de datos de investigación en bibliotecas, <http://bit.ly/RDAthing1>
2. El tesoro e-Science presenta y mapea los conceptos más relevantes, <http://bit.ly/RDAthing2>
3. Entiende el ciclo de vida de los datos de investigación gracias al Modelo de custodia del Ciclo de vida del DCC, <http://bit.ly/RDAthing3>
4. MANTRA. Módulos de Formación en línea para gestores de datos de investigación, <http://bit.ly/RDAthing4>
5. Lee la bibliografía más actualizada <http://bit.ly/RDAthings>
6. Ejemplos de guías de recursos creados por bibliotecarios, para saber más sobre gestión de datos en: *SpringShare LibGuide Community Site*, <http://bit.ly/RDAthing6>

Recursos de aprendizaje  
Datos de referencia y divulgación  
Planes de Gestión de Datos  
Alfabetización en datos  
Cómo citar datos  
Metadatos  
Licencias y Privacidad de los datos  
Preservación Digital  
Repositorios de datos  
y una Comunidad de práctica...

...para ayudar a los bibliotecarios a involucrarse en la gestión de datos de investigación

### Datos de Referencia y divulgación

Los bibliotecarios responden preguntas sobre datos, y realizan actividades de difusión para conocer las necesidades de investigadores y estudiantes en relación a los datos.

7. Comienza una conversación con un investigador sobre datos: Realiza entrevistas sobre datos de investigación <http://bit.ly/RDAthing7>
8. Aprende más sobre las necesidades de los investigadores, leyendo o creando un perfil nuevo Perfiles de Custodia/gestión de datos (por disciplinas), <http://bit.ly/RDAthing8>
9. Crea materiales atractivos para ayudar a tus bibliotecarios, p. ej. Kit de Difusión para bibliotecarios (DataOne), <http://bit.ly/RDAthing9>

10. Preguntas sobre datos contestadas por expertos en el foro DataQ, <http://bit.ly/RDAthing10>

### Planes de Gestión de Datos

Los bibliotecarios están al tanto de los requisitos de las instituciones que financian la investigación y se reúnen con los investigadores para ayudarles a redactar e implementar planes de gestión de datos eficaces.

11. Herramientas que se adaptan a los requisitos de las agencias de financiación y permiten crear un plan, a partir de preguntas dirigidas a los investigadores: DMPTool (USA) <http://bit.ly/RDAthing11>  
PGDOnline (Spain) <http://bit.ly/PGDOnline>

### Alfabetización en Datos

Los bibliotecarios incluyen, cada vez más, en sus actividades de alfabetización informacional, la formación en datos, de tal forma que los usuarios reconozcan cuándo necesitan datos y sean capaces de localizarlos, evaluarlos y utilizarlos.

12. En el Proyecto (y en el libro) *Data Information Literacy* se desarrolla un currículo para ayudar a los bibliotecarios y profesores a incorporar los datos, en la divulgación y en los cursos de alfabetización informacional, <http://bit.ly/RDAthing12>

### Metadatos

Los bibliotecarios ayudan a organizar, clasificar y describir datos de investigación, y desarrollan estándares de metadatos para hacer que los datos sean más fáciles de localizar, entender y preservar.

13. Utilizando el Directorio de Estándares de Metadatos, podrás decidir qué modelo de metadatos normalizado es más apropiado, para recomendarlo o aplicarlo, <http://bit.ly/RDAthing13>

### Cómo citar datos

Los bibliotecarios ayudan a promover el reconocimiento académico de los datos: impulsando y facilitando que sean citables, asignando identificadores a los conjuntos de datos, creando enlaces entre datos y documentos y ayudando a que los usuarios den el reconocimiento apropiado a los productores de datos.

14. DataCite tiene diferentes recursos para ayudar a que los investigadores hagan sus datos citables, y se les reconozca, y para que se empiece a medir el impacto a partir de la asignación de DOIs a los conjuntos de datos (*datasets*) <http://bit.ly/RDAthing14>

### Licencias y Privacidad de los datos

Los bibliotecarios ayudan a los investigadores a compartir sus datos utilizando las licencias apropiadas, al mismo tiempo que protegen la confidencialidad de la información de las personas, o cualquier otro dato sensible.

15. Cómo atribuir Licencias a los Datos de Investigación del *Digital Curation Centre* puede servir para que los bibliotecarios ayuden a los investigadores a elegir la licencia adecuada para los datos que comparten, <http://bit.ly/RDAthing15>

16. El JISC gestiona la lista de correo DATA-PROTECTION donde se discuten aspectos relacionados con datos sensibles, <http://bit.ly/RDAthing16>

### Preservación Digital

Los bibliotecarios están trabajando con la comunidad archivística para desarrollar e implementar la infraestructura y las prácticas que aseguren que las colecciones de datos son accesibles y utilizables en 5, 20, 50, 100 años, o más.

17. Entender vocabularios y estándares para archivos digitales, utilizando el modelo de referencia *OAIS* (*Open Archival Information System*) y certificaciones de repositorios digitales reconocidas como la *ISO 16363* y el *Data Seal of Approval*

18. Puedes encontrar herramientas que te ayudarán en la preservación digital en: COPT, <http://bit.ly/RDAthing18>

### Repositorios de datos

Muchas bibliotecas proporcionan a sus usuarios repositorios para publicar y archivar *datasets*, o para ayudar a los investigadores a identificar otros repositorios (por criterios como: fuente de financiación, disciplina u otros dominios).

19. Encuentra el repositorio adecuado buscando en el Registro de Repositorios de Datos de Investigación *re3data.org* <http://bit.ly/RDAthing19>
20. Publica y comparte datos utilizando repositorios de datos gratuitos como: *Figshare*, *Zenodo*, *Open Science Framework* o *DataVerse*

### Comunidades de práctica

Los bibliotecarios se están conectando entre ellos, y también con una comunidad más amplia de

investigadores, tecnólogos, instituciones de financiación, editores, etc. para desarrollar soluciones y compartir buenas prácticas de gestión de datos de investigación

21. Un ejemplo de enfoque distribuido para la creación de comunidades de gestión de datos de investigación a nivel federal, es el *Australian National Data Service*, <http://bit.ly/RDAthing21>
22. Algunas conferencias que tratan sobre datos de investigación e implican a los bibliotecarios son: *International Digital Curation Conference (IDCC)*, *Research Data Access & Preservation Summit (RDAP)*, *International Association for Social Science and Information Services & Technology (IASSIST)*, y *Research Data Alliance (RDA)*

### Únete a la Research Data Alliance!

Pertenecer a una comunidad internacional que construye puentes sociales y técnicos para el intercambio de datos. Te puedes unir gratuitamente visitando el sitio web, y luego, suscríbete al Grupo de Interés sobre *Bibliotecas para Datos de Investigación*, <http://bit.ly/RDAthing23>

### Información de Contacto

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Gràcies!